RESIDENT EXPERIENCE WITH NURSING HOME CARE: A LITERATURE REVIEW

Prepared by:

W. Sherman Edwards
Priyanthi Silva
Vasudha Narayanan

Submitted to:

Agency for Healthcare Research and Quality
2101 East Jefferson Street
Room 502
Rockville, MD 20852

Submitted by:

Westat
1650 Research Boulevard
Rockville, MD 20850

July 2000

TABLE OF CONTENTS

INTRODUCTION

Approaches to assessing quality of care have been built on Donabedian's three-part approach to quality assessment. The crux of this theory is that there must be a linkage between structure, process, and outcome for any quality assessment to take place; where structure denotes the attributes of the settings in which care is given, process refers to what is done in providing and receiving care, and outcome is the effect of care on the health status of the patient/population (Donabedian, 1988). Considerable research has been conducted to relate organizational characteristics such as nursing home size, expenditure, and staffing patterns to quality indicators. A growing portion of this research has considered resident perception of the quality of care they received. Work done over the last decade has firmly established patient experience as a quality indicator. There are a number of projects underway to report health plan quality to consumers to assist them in selection of health plans. To name a few, the following purchasers report the results of CAHPS surveys to their consumers: the Office of Personnel Management (OPM); the Health Care Financing Administration (HCFA); State Medicaid agencies, including Oklahoma, Utah, Washington, and Iowa; and purchasing coalitions like Buyers Health Care Action Group in Minnesota.

One of the nursing home report card activities underway uses quality indicators derived from the Minimum Data Set (MDS). The MDS is one of the components of HCFA's Resident Assessment Instrument (RAI) that helps facility staff gather definitive information on a resident's needs to be addressed in an individualized care plan. It also assists staff in evaluating goal achievement and revise care plans accordingly by enabling the facility to track changes in the resident's status. In addition to being used to develop care plans, the data are used to monitor care quality and resident outcomes. However, the MDS has been criticized for a lack of a consumer perspective and a "human face" (Uman, 1997).

The idea of studying nursing home residents' perception of quality of care has recently gained momentum (Kruzich, 2000). Nursing homes are considered to enhance the quality of life of residents when they provide a warm, home-like environment, allowing the greatest potential for independence and self-direction in daily activities. The opinions of residents are all the more important because the care received affects the quality of their daily life (Grant et al., 1996). But as Case (1996) noted, any attempt to measure quality in long-term care must be based on a defensible consumer-based definition of quality. The system must not only reflect consumer needs but also must do so in a way that results in a definition that is accepted and agreed on by customer groups, including residents, family members, regulators, payers, and consumer advocates.

This literature review assumes that resident satisfaction and experience with nursing homes is a critical measure of nursing home quality. Specifically, the review covers the following topics:

- Key nursing home satisfaction surveys that have shaped the science to date;
- Domains that these resident surveys have covered and a description of key domains;
- Surveys of family members;
- Sampling of residents and appropriatness of sampling surrogates/proxies;
- Use of cognitive screens to sample residents for the survey;

- Use of proxies to respond to the survey;
- Data collection issues, including mode, issues in interviewing cognitively impaired residents, and selection and training of interviewers;
- Appropriate question format; and
- Hurdles to achieving reasonable response rates.

Literature Review Process

The review process first started with defining broad topics of interest for the team, which also matched topics used in interviews with experts. The topics are as follows:

- Surveys and survey content
- Sampling
- Cognitive screening and proxies
- Data collection protocol and question format
- Response rates

We then developed an inventory, using these topics, of relevant papers, articles, and presentations from a number of sources:

- CAHPS Grantees
- HCFA and AHRQ
- Cross references from collected articles and papers

We also conducted an additional database search to determine completeness of inventory and surface additional relevant documents. The following databases were used:

Medicine and health [MEDLINE, HealthSTAR (Health Services, Technology, Administration, and Research), Mental Health Abstracts, Rehabdata, PsycINFO: Psychological Abstracts, NIAAA/ETOH, IAC Health Periodicals Database]

Economic and related social science research [EconLit, Insurance Periodicals Index, ABI/INFORM, IAC Business A.R.T.S. (Applied Research, Theory, and Scholarship), SocialSciSearch, Sociological Abstracts, PAIS (Public Affairs Information Service), Dissertation Abstracts]

Legislation and Government-sponsored research [Federal Register, Insurance Periodicals Index, IAC Legal Resources Index, PAIS, NCJRS (National Criminal Justice Reference Service), GPO Publications, NTIS (National Technical Information Service)]

Keywords. Keywords used for each topic were:

Use of Proxies: proxy responses, proxy reporting, cognitive impairment, assessment instruments, caregivers/standards, caregivers/classification, caregivers/satisfaction, proxy responses/quality of life, patient-proxy response;

Cognitive Screens: cognitive impairment, dementia/measurement, cognitive assessment, Alzheimer's assessment, independent living skills, patient perceptions/satisfaction, nursing home resident/assessment, dementia care mapping;

Surveys: surveys, patient satisfaction, satisfaction surveys, client satisfaction, resident satisfaction, quality assurance/standards, resident assessment, assessment instruments, survey methods, research methods, consumer assessment, outcome assessment;

Survey Content quality of care/indicators, quality assessment, quality assurance, long term care/standards, nursing home evaluation, homes for the aged;

Mode of Data Collection: research methods, survey methods, data collection, methodology, evaluation;

Response Rates: response rate, survey response rates/refusal/drop out, data collection, survey methods, survey nonresponse.

While reviewing the surveys we also developed an item pool of all questions used in the various nursing home satisfaction surveys. Appendix A includes a sample of questions extracted from this item pool of more than 1,000 questions.

OVERVIEW OF RESIDENT SATISFACTION SURVEYS

The surveys researched for the literature review included those focusing on resident and family member experience or satisfaction with nursing homes. In addition, we looked at the MDS and Sickness Impact Profile (SIP), which do not focus on resident satisfaction but assess the quality of resident care. In some resident satisfaction surveys, the MDS has been used as a cognitive screen to determine if a resident is eligible for an in-person interview. (See section *Use of Cognitive Screens.*)

The surveys in the review include those developed for wide use by the American Health Care Association (AHCA), proprietary surveys developed by nursing homes for their own use like those of Hebrew Home of Greater Washington or Manor Care, and proprietary surveys developed by independent researchers. In addition, the review includes results of pilot studies or other research studies like those of Davis et al. (1997) or Zinn et al. (1993). Below is a summary of some of the surveys that are referred to in the sections on *Domains of Resident Satisfaction.* Appendix B includes a detailed table of 17 surveys and studies.

Zinn et al. (1993), Nursing Home Resident Satisfaction Survey (NHRSS)

The NHRSS was a pilot study to measure resident satisfaction with care. The questionnaire includes three domains of three items each and a global satisfaction item. The survey was developed by Zinn, Lavizzo-Mourey, and Taylor (1993) and supported by a grant from the Robert Wood Johnson Foundation.

Mode	In person interviews
Respondent	Nursing home residents
Cognitive screens	Included residents who were able to respond orally and in English
Sampling	Four nursing homes in the Philadelphia area; 198 eligible residents; achieved an 85 percent response rate
Survey domains	Physician and nursing services, technical skills, environment (meals, room, privacy, schedule), global satisfaction
Response scale	Yes/No; Very Good, Good, OK, Not So Good
Length	11 items

American Health Care Association (AHCA) Satisfaction Assessment Questionnaire (For cognitively intact residents, family members of residents with mild dementia, and family members of cognitively intact residents)

The purpose of this study was to create long-term specific customer satisfaction instruments, determine factors of satisfaction among customers, and determine current levels of customer satisfaction among long-term care customers. It was developed by Gallup and Gustafson & Associates.

Mode	In-person for residents and by mail for family members
Respondent	Cognitively intact nursing facility residents
Cognitive screens	Not Known
Sampling	2,500 facilities/300 cognitively intact residents, 300 residents with mild dementia, and 300 family members of cognitively intact residents
Survey domains for cognitively intact residents	Family and community involvement; independence and respect; programs; facility and setting; meals and dining; health care; doctor's care; nursing staff; safety and security; roommates and other residents; moving in/out of the facility; global satisfaction
Survey domains for family members of residents with mild dementia	Family adaptation; family, friends and community; independence and respect; nursing facility program; nursing facility setting; meals and dining; health care; doctor's care; nursing staff; toileting; nursing facility management; safety and security; relationship with other residents; moving in/out survey; death issues; global satisfaction
Survey domains for family members of cognitively intact residents	Family adaptation; resident adaptation; community involvement; independence and respect; nursing facility programs; health care/doctor care; toileting; nursing staff; nursing facility management; safety and security; relationship with others residents; moving in/out of nursing facility; meals and dining; global satisfaction
Response scale	Excellent, Very Good, Good, Fair, Poor
Length	100-plus items

Ohio Healthcare Association (OHCA)

The OHCA offers satisfaction surveys to its membership twice a year at no cost. Currently about 200 of the 575 members take advantage of this service. This effort was started in 1996 to supplement MDS data. OHCA adapted the 100-plus AHCA survey to a 21-item questionnaire.

Mode	Mail or phone for short-term residents who are interviewed post discharge; in-person for long-term care
Respondent	Residents and family member
Cognitive screens	Use MDS data to screen for those who are cognitively aware
Sampling	Not Known
Survey domains	Living environment, health care, independence, food and dining, emotional support, visitors
List of response	Yes/No; and Very Satisfied, Satisfied, Dissatisfied, and Very Dissatisfied
Length	21 items

Davis et al. (1997), Nursing Home Service Quality Inventory

Independent studies using a multiple-facility sample that supported a four-factor structure of the quality of nursing home service. This study drew on Spalding's (1985) study, which was sponsored by the National Citizens Coalition for Nursing Home Reform. The Nursing Home Service Quality Inventory was developed by Davis, Sebastian, and Tschetter (1997) under a grant from Carroll Martin Gatton College of Business and Economics of the University of Kentucky.

Mode	In-person interviews
Respondent:	Nursing home residents—long-term stay
Cognitive screens	Residents with a score lower than 22 on the Mini-Mental Status Examination were dropped
Sampling	In Round 1, 103 residents from 23 facilities in the Bluegrass Area Development District of Kentucky were chosen. In Round 2, 194 male residents were chosen from a Veterans Affairs Medical Center Long-Term Care Facility in a southeastern city.
Survey domains	Staff and environmental responsiveness; dependability and trust, personal control, food-related services and resources
Response scale	Excellent, satisfaction scales
Length	32 items

Sickness Impact Profile (SIP)

SIP is a self-reported measure of perceived health status providing a descriptive profile of the effects of ill health on behavior. The items describe changes in performance rather than ability. SIP has been used and validated in a number of demographic subgroups, types and severity of illness, and in an interviewer administered format in nursing home settings. The instrument has been demonstrated to be reliable, valid, and responsive to change over time (Gerety et al., 1994). While it is a useful instrument to use for the frail and institutionalized elderly, it has two primary disadvantages in the nursing home setting: (1) respondent burden (136 questions averaging 40-60 minutes); and (2) entire sections items that are not relevant to the nursing home population. A study by Rothman et al. (1989) indicates that the length did not appear to be a problem for residents who considered it a welcome diversion.

Rothman et al. (1989) and Gerety et al. (1994) have conducted studies to make SIP relevant to the nursing home population. Rothman et al. (1989) concluded that it is feasible to administer SIP to nursing home residents who can respond to an interview. SIP produces reliable and valid health status assessment and provides a comprehensive coverage of the physical dimension of health status when compared to other instruments for this population.

Gerety et al. (1994) attempted a scale reduction by first identifying items that were not applicable to nursing home residents and then inspecting each item for two characteristics: (1) item-total category score correlation, and (2) contribution to coefficient alpha. No item was removed that reduced the correlation of the SIP category score with its respective SIP-NH category score below $r < .90$. Alpha coefficients for the SIP-NH total, subscale, and category scores had to fall within or exceed the upper region of a 95 percent confidence interval about an expected alpha.

The result was a SIP-NH one-half the length of the original instrument. In addition to reducing respondent burden, it is also more representative of illness-related disabilities of nursing home residents. But the SIP-NH sample excluded the severely cognitively impaired residents and has been tested with a small sample only.

Resident Experience and Assessment of Life (REAL)

REAL is a system that incorporates a comprehensive set of instruments for measuring satisfaction of residents and family members with daily life experiences in nursing homes, assisted-living setting, and independent-living communities. It was developed by Vital Research with two grants from National Institutes of Health (NIH) and with endorsement from the American Association of Homes and Services for the Aging (AAHSA). They developed four surveys: Resident Satisfaction Interview (RSI), Assisted Living Survey, Independent Living Survey, and Family Mailed Survey.

Resident Satisfaction Interview

Mode	In-person for residents and mail for family members
Respondent	Both cognitively intact and impaired residents and their family members
Cognitive screens	None
Sampling	257 nursing home residents
Survey domains	Help and assistance, communication with staff, autonomy and choice, companionship, food and environment, safety and security
Response scale	Yes/No
Length	42

Measures, Indicators, and Improvement of Quality of Life (QOL) in Nursing Homes (Under Development)

This study, conducted by the University of Minnesota and funded by HCFA, is currently underway. The purpose of the study is to develop and test measures of QOL that are applicable to the broad range of older residents of nursing homes; develop a data collection strategy; suggest ways that these measures and indicators can be used for regulatory process, for nursing homes performing quality improvement, and for consumer reporting (Kane et al, 2000). The first wave report will be submitted to HCFA in fall 2000.

Mode	In-person for residents and mail for family members
Respondent	Both cognitively intact and impaired residents and their family members
Cognitive screens	None
Sampling	Wave 1: 2000 residents in 40 facilities in Five states-New York, New Jersey, Minnesota, California and Florida
	Wave 2: 60 additional facilities in five states selected on the basis of their performance of key QOL indicators
Survey domains	Dignity, Autonomy and Choices, Individuality, Privacy, Enjoyment, Meaningful activity, Relationships, Comfort, Sense of security, Spiritual Wellbeing, Functional competence
Response scale	Likert scale and Yes/No for residents who cannot handle the Likert scale
Length	140

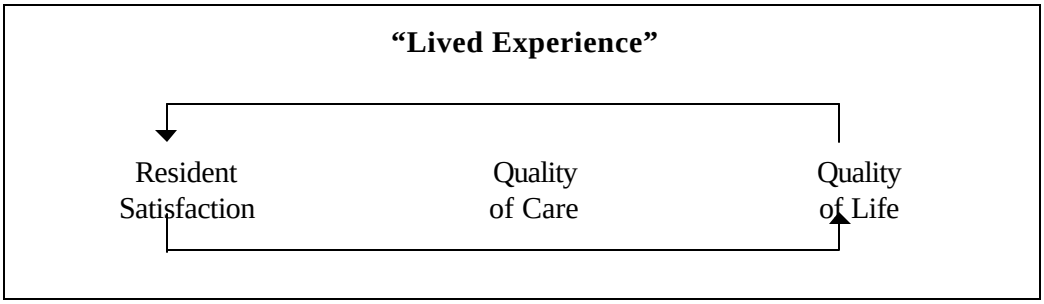
DOMAINS OF RESIDENT SATISFACTION

Introduction

Nursing home care has an idiosyncratic mix of multidisciplinary personnel, structures, and technology. Every staff member in a nursing home plays a role in resident care. To add to the complexity, the goals of nursing home care vary by patient (Kane, R., 1988). While at a global level quality of life is an important aspect of nursing home care, coordination with acute hospital care, mental health, and other community services is also an important aspect of providing patient care.

Probably the most widely used quality measurement instrument is the MDS. There is a general consensus among the MDS development team that the MDS has significantly improved resident care (Schnelle, 1997). While the MDS was meant to generate standardized quantitative data regarding care needs of nursing home residents, there is vast opportunity for interpreting quality of care from these assessments (Rantz et al., 1996). Since these data are collected at regular intervals, the data can be used to monitor care quality, resident outcomes, and quality improvement efforts. However, while MDS data are reported to be reliable since facilities supply the data, some may be more reliable than others (Rantz et al., 1996; Hawes et al., 1995).

In the "lived experience" theory propounded by Rubenstein (2000) the residents' tenure in a nursing home should be measured in a holistic fashion and not piecemeal. The diagram below is a description of the lived experience.



In addition to looking at models for measuring quality of health care and nursing home resident experience, it is worth looking at SERVQUAL. SERVQUAL is a set of service quality dimensions (Reidenbach and Sandifer-Smallwood, 1990; Parasuraman et al., 1988) used extensively in retailing and industrial settings, and a modified version has been applied to a hospital setting. The model can also be extended to nursing home care (Davis et al., 1997). The SERVQUAL dimensions include the following:

- Tangibles or physical facilities,
- Reliability or ability to perform the promised service dependably and accurately,
- Responsiveness or willingness to help customers and provide prompt service,
- Assurance or knowledge and courtesy of employees and the ability to provide trust and confidence, and

- Empathy and/or caring and personalized attention.

Most of the studies that have developed and tested domains of resident care have used focus groups, expert panels, and critical incident[1] techniques to gather information on domains that are important to consumers. However an area of concern in satisfaction surveys is social desirability. Concerns voiced by residents are not necessarily the issues that are of utmost importance. It is easier and safer to complain about food, lost clothing, and other laundry issues than to complain about uncaring or disrespectful staff. In fact, the Soberman et al. (2000) study initially included *laundry* as a domain but subsequently dropped it since residents tend to complain only about what is socially acceptable and safe to complain about and not about things that are most important to them.

Resident's Domains

Domains relevant to residents are not necessarily relevant to family members. Residents experience the nursing facility first hand, while family members are further removed from the day-to-day experiences. However, family members are concerned that their loved ones get the care they need in a home-like atmosphere. This section focuses only on domains relevant to residents. The next section includes a brief review of domains relevant to family members. The domains that have been used most often in studies or surveys are listed below and discussed in this section. Appendix B includes a detailed summary of the studies in which these domains have been used.

- Autonomy and choice
- Safety and security
- Help and assistance
- Interaction with staff/family/friends/other residents
- Communication
- Food
- Environment
- Activities
- Medical services
- Empathy and caring
- Dignity
- Nursing services

Autonomy and choice. When residents were asked to identify and describe factors capable of improving the quality of their lives and the quality of care they received, Spalding (1985) reported that residents value the *ability to exercise control* over their lives. When Davis et al. (1997) conducted a factor analysis to identify domains of satisfaction based on 52 items derived from National Citizens Coalition for Nursing Home Reform (NCCNHR), one of the domains its analysis revealed was *personal control.* In addition Meister and Boyle (1996) and Bleismer and Earl (1993) validated the NCCNHR quality indicators as being important to long-term care. Soberman et al. (2000) use the *autonomy* label to include whether the residents decide what they do each day, whether they are free to come and go as

[1] In a critical incident technique, the respondent is asked to provide descriptions of specific incidents he/she perceive to be significant to the topic being studied.

they please, whether they are provided equipment that enables them to be independent, and whether they are forced to do things they don't want to do. Uman et al. (2000) have shown that this domain is valid and reliable among both the cognitively intact and impaired.

Safety and security. In order to be able to exercise personal control, nursing home residents need to feel safe and secure and have a safe place to wander indoors and out-of-doors (Rantz et al., 1998). This domain includes whether there is adequate surveillance at night, nutritional status, and response to changes in the health status of the resident (Grant et al., 1996).

Help and assistance. Davis et al. (1997) have used the domain *staff and environment responsiveness* in the NH Service Quality Inventory. The domain includes whether the staff deal patiently and courteously with residents, safety and security of residents, whether the staff listen, and whether problems are resolved quickly. Uman et al. (2000) have shown that this domain is valid and reliable among both the cognitively intact and impaired.

Interaction with staff/family/friends/other residents. One of the key interactions in a nursing home environment is with the staff. In a focus group conducted by Rantz et al. (1998), a participant commented, "Staff really interact with residents and residents are not just sitting in hallways with people ignoring them." This interaction does not merely provide technical care that could be included in "help and assistance" or "nursing services" domains, but it is the human contact as well.

Very often residents believe it is important to be treated as an important adult or to have their "personhood" acknowledged (Grant et al. 1996). Lack of this acknowledgement is dehumanizing. An interview excerpt (Grant et al. 1996) evokes this interaction: "Just like tonight, she was a little down because we couldn't take her home, and a nurse came up and gave her a big hug. The nurse did not overhear our conversation. She just came in and seen that Ma was a bit down and she just put her arm around her. *It seemed caring*."

As described by Rantz et al. (1998), good quality staff interact positively with residents and help residents meet their needs. Such interaction is both social and therapeutic (Grant et al., 1996), and it is difficult to define where one leaves off and the other begins. Uman et al. (1999) use the label companionship to capture the measures within this domain.

Food. Variations of the food domain have been included in a few studies. Davis et al. (1992), used a *food-related services and resources* domain in the NH Service Quality Inventory. It was also validated by Meister and Boyle (1996) and Bleismer and Earl (1993) as being important to long-term care. In the Davis et al. (1997) study, this domain included whether variety was available, and unless there are dietary restrictions whether there is plenty of food at mealtimes, food temperature, freshness, and the availability of staff to provide care during meals. Koenig and Kleinsorge (1994) included *food services* in their surveys for residents and families. And Soberman et al. (2000) included taste, temperature, and variety of the food in their survey.

Environment. The true definition of environment is how the facility is maintained, which means being odor free and clean (Grau et al., 1995), with sufficient bright lighting. All these aspects of the environment are related to the kind of care the resident receives. If there are strong odors, the staff are not providing good care (Rantz et al., 1998). Soberman et al. (2000) use the environment domain in a broader sense and include in it *physical surroundings, rooms, nursing units, odor, noise, safety of the environment, home-like environment.* Grant et al. (1996) also use the *home-like environment* analogy. Zinn et al., (1993) include *privacy and quiet* in this domain.

Activities. Activities that help keep residents mobile and engaged are critical to their care. The need for activity can vary depending on levels of cognitive impairment, but mobility and activity are particularly important for the cognitively intact (Uman et al., 2000).

In the Rantz et al. (1995), *Models of Good Quality*, *milieu* is treated as a separate domain and in a way straddles both the *environment and activities* domains. Milieu includes a calm but active and friendly atmosphere. The other aspects of "milieu" are the presence of community volunteers, animals and children, and whether residents engaged in age- and functionally appropriate activities.

Zinn et al. (1993) consider activities as *other services* and ask one question in this domain: Does the resident like his/her daily schedule? Soberman et al. (2000) include different types of activities like trips, activities that engage the mind, time and location of activities, and whether necessary help is provided to perform the activity.

Medical services (e.g., rehabilitation, maintenance, professional services, etc.). Spalding et al. (1985) reported that residents value whether they are cared for by technically competent staff. Zinn et al. (1993) ask whether the medical staff treat residents well, whether they are responsive, and if the residents have confidence in them. The focus of the questions in this domain is on what the resident can respond to. Residents are usually not in position to respond to the technical competence of the staff or about their care plan.

Empathy and caring. Empathy and caring could either be treated as a separate domain as in the Kleinsorg and Koenig (1991) survey or as in Grau et al. (1995). It can also be considered as an aspect of staff interaction with the resident (discussed under *interaction with staff/family/friends/other residents).*

Dignity. Similarly, dignity can either be considered an aspect of interaction or treated separately on its own as in the Spalding et al. (1985) study or the Soberman et al. (2000) survey. Initially, the Soberman study included dignity under nursing services but moved it to a separate domain, in spite of a high correlation between the two, feeling it deserved separate mention.

Nursing services. In the Grau et al. (1995) study, when respondents were asked to describe their best and worst experiences since nursing home placement, they seemed to have had a better experience with professional staff, nurses, physicians, and therapists, than with nurse aides or nonprofessional staff. Most of the negative experiences were associated with nursing aides. The aides

perform a number of "bed and body" functions that invade personal privacy, possibly increasing resident's sensitivity to the manner in which this care is provided.

Zinn et al. (1993) include three questions under nursing services: treating the resident well, responsiveness to calls, and confidence.

Addressing Family Members

Family members are as much a customer of nursing homes as the resident and may be the ones making the choice of a nursing home. However, there are only a few studies that have developed domains applicable to family members. Family members want residents to get the care they wish they could give. While they feel relieved of the burden of care, the concern about their care can also be a burden. (Grant et al., 1996). Both residents and their family members want good quality care but have differing perspectives on what is important.

As survey respondents, family members can provide information about the resident before they were admitted and information about their personal requirements or medical condition. They are also the best advocate for the resident and play a key role while interacting with other residents and staff (Grant et al., 1996). A number of surveys use family members as surrogates for the resident and administer the resident survey to the family member. See "Use of Proxy Respondent" section later in this report. Soberman et al. (2000) have demonstrated in their study that family members were unable to provide accurate surrogate data and developed a separate survey for family members.

The Family Perceptions Tool (FPT) was developed by Maas, Buckwalter, and Russell (1986). The domains included staff caregivers' knowledge; available resources; care environment; nursing care; care by professions other than nursing; and relationships of staff to patients and family members. However, Maas, Buckwalter, and Russell (1986) acknowledge the need for more work on family members' perceptions of resident care following institutionalization.

SAMPLING

Generally, the nursing home satisfaction studies referenced in the literature are conducted with a small group of facilities, either purposively selected or constituting some reference population of facilities from which all residents are included. Residents are typically selected in simple random or systematic samples; sometimes separate samples are taken from different units within a facility. The most important sampling-related issue identified in the literature is defining what residents are eligible to complete the interview; typically, the concern is whether they are cognitively able to respond (see section on *Cognitive Screening*), although length of and reason for stay may also be a concern. A few exceptions to these general approaches are presented below.

Stratification of facility samples. Mount (1992) describes a survey of medication use employing a sample of nine proprietary and nine nonprofit church-related SNFs in southern Wisconsin. The other facility stratification criterion was percentage of private-pay patients (above and below the mean).

Stratification of resident samples. Simmons et al., (1997) describe stratifying a sample of two homes' residents according to the Cognitive Performance Scale (CPS). The purpose of this study was to determine what proportion of nonprescreened residents could answer simple "yes/no" questions, what proportion could do so accurately, and whether information available from nursing home records could reliably identify those who were unable to answer or unable to answer accurately.

Coverage–surrogate respondents. There seems to be general agreement that next of kin or other proxy respondents are not appropriate substitutes for residents. As discussed in detail in the next section, proxies introduce a bias, and if proxies are inevitable, it is essential to understand the direction of the bias (Magaziner, 1997). If proxies were to be used, coverage would be an issue. In a study to evaluate the agreement between residents' and surrogates' (family or friends) perceptions of residents' satisfaction with nursing home care, Lavizzo-Mourey et al., (1992) identified 168 residents among 480 (35 percent) who met the criteria for eligibility: the ability to respond to questions, in English; having a family member or friend designated as responsible party in the medical record; and to consent to an interview. The study concluded that surrogate respondents cannot accurately express the residents' satisfaction with all areas of health care and that their evaluation should not be used in lieu of the residents' experience.

USE OF COGNITIVE SCREENS

Quality of life and medical care provided to nursing home residents have become a priority as more and more people live longer with chronic conditions (Simmons et al., 1997). As a result, resident satisfaction with nursing home care has become a very important subject (McDaniel and Nash, 1990; Pearson et al., 1993; Zinn et al., 1993). More than 50 percent of the 1.6 million nursing home residents in the United States are cognitively impaired (Morris et al., 1994; Hartmaier et al., 1995; and Becker et al. 1999). As Rapp et al. (1994) reported, "accuracy of diagnosis can become a major stumbling block when screening potential subjects because many nursing home residents are admitted with diagnoses such as dementia, confusion, senile dementia, chronic brain syndrome, and organic brain syndrome. None of these terms are clearly diagnostic and they usually are not supported by the comprehensive testing necessary to make more definitive diagnosis." Conducting research with cognitively impaired elderly presents challenges to researchers in identifying and assessing potential subjects and in maintaining the sample.

Assessments of quality of life among nursing home residents have often been conducted with interviews of residents' family members or nursing home staff rather than with residents because a large number of nursing home residents are reported to be cognitively impaired. Even when nursing home residents have been interviewed, most residents have been excluded from studies due to arbitrary screening criteria or subjective screening (Simmons et al., 1997). Aller and Coeling (1995) excluded 130 out of 142 residents in a qualitative study on quality of life and its meaning to nursing home residents because they did not meet the criteria set by the study. The criteria included being legally competent and judged by a social worker and the director of nursing as being able to participate in a 20-30 minute interview. Mattiasson and Anderson (1997) assessed the quality of nursing home care through interviews with only 18 percent of the residents because the head nurse indicated that they were the only residents who were cognitively oriented to participate in an interview. Thus, large numbers of residents are excluded from studies because they are judged to be cognitively incompetent of being interviewed.

Early Cognitive Test Instruments

Mental functioning is assessed in numerous ways that include unstructured mental status examinations administered by clinicians, semi-structured interviews that allow the respondent's responses to be scored and the interviewer to report observations, as well as self-administered questionnaires that again are scored, and formal psychological tests. The "mental status examination" is a "time-honored method by which psychiatrists and other mental health personnel form judgements about mental functioning in the context of a clinical interview" (Kane and Kane, 1981). One of the early global rating tests (1961) was the Crichton Geriatric Behavioral Rating Scale (Hughes et al., 1982) that attempted to specify levels of global functioning. But this test was not well suited to study cognitive loss. Hughes et al. (1982) developed a Clinical Dementia Rating (CDR), which offered more detail and could be used by neurologists, psychiatrists, psychologists, and others experienced in assessing cognition of the elderly. The CDR focused on cognitive function and not on disability arising from medical, social, or emotional problems. It had six behavioral and cognitive categories that are combined to make one global CDR.

Pfeiffer (1975) reported the development of the Short Portable Mental Status Questionnaire (SPMSQ), which was able to test several diverse aspects of intellectual functioning, including short- and

long-term memory, orientation to surroundings, information about current events, and the ability to perform serial mathematical tasks. It was a 10-item scale that ranged from intact functioning to severe impairment and measured the influence on test performance of demographic factors (educational attainment, race, and sex).

Historically, most nursing homes in the United States maintained only limited information on the residents' functional status and cognition (Morris et al., 1990). The 1987 Omnibus Reconciliation Act changed this practice. It requires all Medicare and Medicaid certified nursing homes in the United States to complete a standardized assessment of each resident's functional, medical, psychosocial, and cognitive status, or RAI. Its care assessment component is the MDS (Hartmaier et al. 1995; Morris et al., 1990). The Mini-Mental Status Examination (MMSE), Cognitive Performance Scale (CPS), Global Deterioration Scale (GDS), and the Minimum Data Set - Cognition Scale (MDS-COGS) are some of the commonly administered tests of mental status/cognitive ability (Rapp et al., 1994; Hartmaier et al. 1994).

Minimum Data Set (MDS)

The MDS (as described earlier), a new performance-based assessment tool, is comprehensive, uses standardized definitions, and includes items that measure a resident's deficits, strengths, and preferences. Trained clinical professionals such as nurses, social workers, and therapists assess resident performance during different times of the day over all shifts during the prior 7-day period and interact directly with the resident. They also review resident records and gather information from direct care and licensed professional staff during this time (Morris et al., 1994). An appropriate care program is developed for each resident after the MDS assessments are completed. MDS assessments are required at the time of admission, every 3 months following admission, and on any significant change in the resident's status such as a hospital admission or when a resident experiences a change in his/her health status. MDS assessments are part of the resident's permanent medical record. The MDS provides a common terminology of resident assessment across facilities and includes seven direct measures of cognition: short-term memory, long-term memory, recall or orientation of items (season, location of room, staff names and faces, orientation to nursing home), and decisionmaking ability (See Table 1, which shows the cognitive rating scores generated by the MDS). In addition, a number of indirect measures of cognition are also included: comatose status, communication skills, eight measures of activities of daily living performance, problem behavior and level of continence (Hartmaier et al., 1995). Simmons et al. (1997), who investigated whether it is possible to identify residents as being "accurate responders" using descriptive information (MDS data) available in nursing homes concluded that 60 percent of nursing home residents are capable of responding to simple yes or no questions regarding the daily care they receive and to their life experiences in the nursing home. They caution researchers that the MDS variables used had a 80 percent accuracy rate, which means that 20 percent of the time it could yield inaccurate results.

Table 1.

MDS and MDS-COGS Scoring Sheet
(from Hartmaier et al. 1994)

MDS Item	MDS Scoring		MDS-COGS Scoring (max score = 10) *	
Cognitive Patterns				
Short term memory	memory problem =	1	memory problem =	1
	memory OK =	0	memory OK =	0
Long term memory	memory problem =	1	memory problem =	1
	memory OK =	0	memory OK =	0
Location of own room	doesn't recall =	0	doesn't recall =	1
	does recall =	1	does recall =	0
Knows he/she in a nursing home	doesn't recall =	0	doesn't recall =	1
	does recall =		does recall =	0
No orientation items recalled	none recalled =	1	none recalled =	1
	otherwise =	0	otherwise =	0
Decision making	independent =	0	independent =	0
	modified independence =	1	modified independence =	1
	moderately impaired =	2	moderately impaired =	2
	severely impaired =	3	severely impaired =	3
Communication Patterns				
Making self understood	understood =	0	understood =	0
	usually understood =	1	usually understood =	0
	sometimes understood =	2	sometimes understood =	0
	never/rarely understood =	3	never/rarely understood =	1
Physical Functioning				
Dressing self performance	independent =	0	independent =	0
	supervision =	1	supervision =	0
	limited assistance =	2	limited assistance =	0
	extensive assistance =	3	extensive assistance =	0
	total dependence =	4	total dependence =	1

* MDS-COGS = 0, 1 represents cognitively intact-mild impairment.
MDS-COGS 2, 3, 4 represents mild-moderate impairment.
MDS-COGS = 5, 6, 7, 8 represents moderate-severe impairment.

MDS-COGS = 9, 10 represents severe-very severe impairment.

Minimum Data Set-Cognition Scale (MDS–COGS)

Since cognitive status is a continuum, Hartmaier et al. (1994) developed a continuous measure to evaluate cognition utilizing the MDS items. This new scale, the MDS Cognition Scale (MDS-COGS) combines eight MDS items into a 10 point additive scale ranging from no impairment to very severe cognitive impairment. It is reported to be simple, direct, and easy to understand. It uses data routinely collected on nursing home residents in the MDS. Professional or skilled staff is not necessary to administer the MDS-COGS. Interpretation is relatively easy because it has a continuous scale ranging from 0 (no cognitive impairment) to 10 (severe cognitive impairment) (Hartmaier et al. 1994). It also generates cognitive rating scores directly from the MDS, unlike the CPS, which requires MDS items to be placed in a hierarchical tree. (See Table 1, which shows the cognitive rating scores generated by the MDS-COGS.)

Cognitive Performance Scale (CPS)

Although there are several cognitive instruments available to test the severity of dementia, administering them is not always feasible because they need highly skilled personnel to administer them and are very expensive (Hartmaier et al. 1994; 1995). In response to the need for a easy-to-handle, less costly instrument to test the severity of dementia, the MDS Cognitive Performance Scale (CPS) was developed modeled on the Mini-Mental State Examination (MMSE) and the Test for Severe Impairment (TSI) (Morris et al., 1994). The CPS combines selected MDS cognitive items within a hierarchical seven-category rating scale, ranging from no cognitive impairment to very severe impairment. Hartmaier et al., when validating the CPS against the MMSE, found that the CPS overcame many characteristics of other cognitive assessment instruments that limit their use with the nursing home population, such as needing skilled staff, a long time to administer, and high administrative costs. Uman et al. (1999) who conducted a study on the satisfaction of nursing home residents with cognitive impairment reported that substantial usable data could be obtained from CPS levels 0-5. With the CPS, MDS users are reported to be able to assign residents into easily understood cognitive performance categories (Morris et al., 1994). Gruber-Baldini et al. (1999) examined the validity of the MDS on a large sample of residents in nursing homes in situations where the MDS was not completed by trained research staff. They found that the CPS and the MDS-COGS were highly correlated and that both were moderately correlated with the MMSE. They conclude that the CPS and the MDS-COGS appear to be "valid instruments for assessing the cognitive impairment of nursing home residents."

The Mini-Mental State Examination (MMSE)

The MMSE is a brief, general purpose cognitive screening instrument accepted as a reliable and valid test for the identification of cognitively impaired persons in long-term care settings developed by Folstein and his colleges in 1975. It is referred to being "mini" because only cognitive functioning is measured by it (Kane and Kane, 1981). The MMSE can be administered in 5-10 minutes. Scores range from 0 (worst) to 30 (perfect). The MMSE contains two parts. The first part requires verbal responses and covers orientation, memory, and attention. The maximum score is 21. The second part tests the ability to name and follow verbal and written commands, write a sentence spontaneously, and copy a complex polygon. The maximum score is 9 (Folstein et al., 1975). Folstein has recommended a score of 23 as a cut-off point to identify cognitive impairment. However, a lower MMSE cut-off point has been suggested for those with grade 8 or less education. The MMSE has been criticized that it is susceptible to ceiling and

floor effects (Doyl et al., 1986; Davidson et al., 1991; Reed et al., 1989). Brod et al. (1999), who developed an instrument based on their conceptualization of the domains of quality of life appropriate for persons with dementia, reported that it is feasible to assess the quality of life of patients with dementia with a MMSE score greater than 12.

Berlowitz et al. (1995), who assessed health-related quality of life of 213 residents in a Veterans Affairs nursing home, used the Folstein Mini-Mental Status score to decide which residents should be included in the study. Eligibility was determined if the resident had 23 points or higher on the Folstein Mini-Mental Status score.

Mattiasson and Andersson (1997) conducted a survey on the quality of nursing home care assessed by competent nursing home patients decided to allow the head nurse in the facility to make a judgment on which patients were cognitively competent to be selected for the study. They later administered a six-item version of the Folstein Mini-Mental Status to check on orientation and found that three patients had scores in the 3-4 range, which they deemed low. However, these residents were not excluded from the study because communication between the resident and the interviewer was judged to be acceptable.

Global Deterioration Scale (GDS)

Hartmaier et al. (1994) reported that the GDS is one of the most widely used instruments for the clinical assessment of severity of dementia, especially dementia of the Alzheimer's type. It describes seven types of cognition beginning with no cognitive impairment (GDS stage 1) to very severe cognitive impairment (GDS stage 7). Criteria for GDS stages include "the observation of physical and behavioral functioning, performed in a semi standardized manner, guided by GDS sub-scales, the Brief Cognitive Rating Scale (BCRS) and the Functional Assessment Test (FAST).

USE OF PROXY RESPONDENTS

As discussed in the previous section, the principal reason for low response rates in satisfaction surveys of nursing home residents is the physical, cognitive, or emotional limitations of the residents. The inability of the sampled person to respond to a survey instrument has led interviewers to use proxies (a person who is closely associated with the sample person) to respond instead (Epstein et al. 1989; Santos-Eggimann, 1999). From a survey methodology perspective, using proxies to respond because the sampled respondent is unwilling or incapable allows the sample to be more representative and more inclusive (Magaziner et al. 1988). Unless some studies use proxies, the response rates could be very low, and it could be a serious concern for studies where the respondents are impaired. Lavizzo-Mourey et al. (1992) reported that since 47 to 63 percent of nursing home residents have one or more functional or mental disabilities, they often cannot respond to a survey. If not for a proxy response, some studies may never be conducted because of the vulnerability of the sample (Magaziner, 1997, 1992). Using a proxy could also increase the chances of obtaining a more representative sample of the study population (Magaziner, et al., 1996). Evaluating the response comparability between elderly hip fracture patients and interviewer, Magaziner et al. (1988) selected proxies on questionnaire items pertaining to the patient's prefracture, physical health status, and ability to perform essential activities of daily living. They found that including proxies in the sample increased the sample size by 71 percent. But from a practical point of view, the most important issue is whether proxies for nursing home residents can provide useful information and whether "the proxy is a reliable substitute for the patient" (Epstein et al., 1989).

Response Error and Response Bias

A proxy respondent could introduce two types of errors to a survey: response error and response bias. Response error is when the respondent gives an inaccurate response to a question. This could occur more often when the respondent is a proxy because the proxy respondent has to answer the questions for the nursing home resident. He/she might respond inaccurately without knowing what the response of the nursing home resident to a question might be. It is his/her best guess or what he/she thinks the resident would answer. This response error might be remedied by increasing sample sizes to decrease standard errors of estimates. Response bias is when respondents systematically over estimate or under estimate. Bias is introduced because of a respondent's style in answering such as the tendency to agree regardless of the issue or when the respondent is asked questions about topics that he perceives to be highly sensitive, objectionable or threatening. If several proxy respondents answer the same set of questions in a similar manner, the study would have a consistent response bias. Response bias is harder to deal with than response error. Researchers need to understand the direction and the magnitude of the bias so that remedial action could be taken. The best way to avoid response bias would be to ask questions that a proxy would be able to answer without guessing or ask questions where he would be knowledgeable enough to respond to. Avoiding response bias is more difficult but could be minimized if the proxy respondent is asked more specific questions (Magaziner, 1997).

Validity of Proxy Responses

Bias is a very important issue than response error alone. Would the proxy response be the same as what the nursing home resident would have responded had he/she been able? Lavizzo Mourey et al. (1992) found that the ability of the proxy to represent a nursing home resident's satisfaction with the care in the nursing home is limited and inconsistent. Proxy respondents could not accurately or informatively express nursing home residents' general satisfaction with nursing services and the environment. Overall they report that when nursing home residents are unable to discuss their perceptions with the proxy, the Dorman et al. (1997) proxy responses would not give an accurate picture found that proxy assessment of social functioning, pain, and overall health-related quality of life were associated with more error and recommend interpreting such data with care. Proxy assessment of psychological functioning according to Dorman et al. (1997) was the least reliable. Mosley and Wolinsky (1986) reported that when more specific symptoms, conditions, or functional impairments were questioned, the proxy responses were not as reliable.

A large number of studies have found that proxy responses are not only inaccurate but also biased (consistently wrong in one direction or another). Many studies show proxy responses describe worse health and worse emotional status for patients (Epstein et al., 1989; Rothman et al., 1991; Berlowitz, 1995; and Grootendorst et al., 1997). Agreement between the subject and the proxy is reported to be worse when the questions concern complex tasks that could be interpreted differently by the resident and the proxy. Magaziner (1997) has sited an example where talking on the telephone could be interpreted by the two respondents differently. One might think that placing the call and completing the entire task as being what is meant by talking on the telephone while the other might interpret it as talking when someone dials the number for them. Magaziner (1997) reports that agreement and bias are a function of three factors and their interactions:

- The subject being asked about (health or functional status) and the manner in which specific questions are asked;
- The characteristics of the subject, and his/her health staus;
- Characteristics of the proxy and the proxy's relationship to the subject about whom information is being collected.

In some studies respondents report more health problems than proxies reporting on the sample person. Kovar and Wright (1973) found that self-respondents reported higher on 6 of the 10 indicators of illness, disability, and outpatient utilization. Haase and Wilson (1972) found that self-respondents reported more days in bed and more physician visits than the proxies.

Several researchers have pointed out that proxies tend to report more disability than subjects report for themselves when measuring chronic conditions, physical and instrumental functioning, and affective status (Magaziner, 1992; Sprangers and Aaronson, 1992; Zimmerman and Magaziner, 1994; Rubenstein et al., 1984; Clipp and Elder, 1987; Magaziner et al., 1987, 1988, 1996; Rogers and Herzog, 1989; Bassett et al., 1990).

A significant number of studies have found that proxy – resident agreement is worse when the resident is cognitively impaired (Kommer et al., 1997; Dorman et al., 1997; Weinberger et al., 1992; Magaziner et al., 1996; Magaziner et al., 1988). Kommer et al. also found that within a cohort of residents and their proxies, agreement deteriorated as time elapsed and the physical and neurological conditions deteriorated.

Factors reported to influence response agreement and/or bias among proxies and respondents are reported to be age, gender, relationship to subject, degree of care giving assistance provided, amount of contact between the proxy and the respondent, whether they live together and the duration of their relationship (Magaziner, 1992; Sprangers and Aaronson, 1992; Zimmerman and Magaziner, 1994; Rubenstein et al., 1984; Clipp and Elder, 1987; Magaziner et al., 1988, 1996; Rogers and Herzog, 1989). Magaziner (1996) examining bias on measures of chronic conditions found that proxies who were younger than 60 years, better educated, children of the subjects, and not living with the subject but visited frequently were more likely to over report the presence of health conditions of the sample person.

In an ideal situation the preferred proxy is someone who maintains close contact with the patient but who does not provide daily care because the proxy providing daily care might exaggerate the disabilities of the patient (Magaziner et al, 1996). However, many nursing home residents do not have such preferred candidates.

What can a proxy report accurately

It is reported that agreement between subject and a proxy is best when questions are asked concerning behaviors, functions, diagnoses, conditions, and signs and symptoms with observable manifestations (such as presence of chronic bronchitis, back pain, paralysis, and walking ability) (Magaziner, 1992; 1997; Magaziner et al. 1987; 1988; 1996; Epstein et al., 1989). Agreement between the two is reported to be highest for questions related to medical conditions, ADL and IADLs. Dorman et al. (1997) found that among a group of stroke patients, the responses between patients and their proxies agreed reasonably well when they were asked about health-related quality of life questions related to mobility and self-care.

Bias introduced by proxies-health care providers

Sometimes health care providers focus on negative aspects of a patient's health and underrate the patients' assessments of themselves when responding as proxies. Sainfort et al. (1996) who used a convenient sample of schizophrenic patients and their health care providers to assess the quality of life of the patients found that clinicians often perceive symptoms to be the major indicator of patient's well-being. The study showed moderate agreement only between providers' and patients' assessment of symptoms and no agreement on other dimensions of well-being. They point out that depending on the responses, the interventions given to a patient could be very different. Slevin et al. (1988) who studied doctors and health professional's assessment of cancer patients' quality of life found that the correlation between the responses of the health care providers and patients was poor. This lead the researchers to conclude that if

a reliable and consistent method of measuring quality of life in cancer patients is required, the patients have to respond and not the health care providers.

Berlowitz et al. (1995) report that physicians and nurses should not be used as proxies because they have limited insight into patients' health-related quality of life. They stress that patient-based assessments are the ideal and that one must be very cautious when provider proxies are used where patient-based assessments are not possible. Health care providers who respond as proxies give different responses to those from the sample respondent who could be a patient or a nursing home resident in their assessment of the health status of nursing home residents (Tennstedt et al., 1992). This is because health care providers are especially trained to assess and evaluate health status. They see the patients very regularly and their responses would be based on clinical diagnoses.

Uhlmann and Pearlman (1991), who examined 258 chronically ill elderly outpatients from the VA, an HMO, and physician practices in Pacific Northwest, found that physicians rated patients global quality of life, physical comfort, mobility, depression, anxiety, and family relationships significantly worse than patients did. The physician assessments were associated with their attitudes toward life-sustaining treatment. Whereas for patients, treatment preferences were independent of both global and dimensional quality of life. Ouslander et al. (1989) asked 70 volunteer residents, four proxies (closest relative, a nurse, a social worker, and a physician) to make health care decisions after being presented with four clinical vignettes, two high-risk procedures (aortic valve replacement and carotid endarterectomy) and two low-risk (flu vaccination and psychotropic medication) found low overall Agreement between residents and proxies. They found worst agreement with physicians on high-risk procedures. Sprangers and Aaronson (1992) who investigated to what extent providers and family proxies can assess accurately and under what conditions is inclusion of proxy ratings warranted found that both health care providers and significant others underestimate quality of life. Health care providers and significant others were equally inaccurate and that health care providers underestimated pain.

Special groups

As Binstock (1992) pointed out, dementia involves progressive cognitive and functional decline, which, in the late stages of the disease, finally makes it impossible for the demented person to experience the world in many ways as other people take for granted in daily life. Some researchers argue that a proxy is essential to conduct research with special groups of respondents such as Alzheimer's patients, stroke patients, and persons with severe dementia. Because of memory decline and loss of verbal skills, patients diagnosed with Alzheimer's disease often cannot describe the impact of disease and may not perceive subjective states of well-being as a person without Alzheimer's disease might (Albert et al., 1999).

However, it is clear that using responses of the sampled resident is the best method of obtaining information of their experience with nursing home care. Even if residents with severe dementia are unable to respond, the proxy response will introduce a bias. An option, in such cases, is to develop a different set of questions directed toward the family so that the family's opinions of the resident's quality of care could be measured. And as we have emphasized earlier, the family member is an important customer of a nursing home, and their opinions should not be ignored.

DATA COLLECTION PROTOCOL

Mode of Interview

A substantial body of literature has examined differences in mode of interview, including differences in cost, in the nature of responses, and in respondent preferences. While most of these studies are of general population samples, many included only or a majority of older persons. In a review of methodological research on mode of interview for older populations, Herzog and Kulka (1989) found no persuasive evidence of the superiority of one mode over another. Among more recent studies supporting Herzog and Kulka's conclusion, Morishita et al. (1995) found good concurrent validity administering the SIP and the Geriatric Depression Scale in person and on the telephone. In an experiment comparing in-person and telephone interviews with 65 patients with peripheral arterial occlusive disease, Van Wijck et al. (1998) found no difference in time-tradeoff and standard gamble measures of quality of life. Korner-Bitensky et al (1994) found few differences between telephone and personal interviews of former rehabilitation patients on health status scales. One comparison of in-person and telephone interviewing of elderly respondents, for the SF-36, found "large nonsystematic differences" between responses by mode (Weinberger et al, 1994); the authors were unable to explain these differences. However, none of the studies comparing modes were conducted with nursing home residents.

In fact, all studies of nursing home residents described in the literature (see Appendix B and Appendix C) have employed face-to-face interviewing. Ejaz (2000), in an overview of conducting satisfaction surveys in nursing homes, recommends only the face-to-face interview. In addition, a survey of Ohio nursing facilities that inquired about the use of satisfaction surveys found that long-term care residents generally received in-person interviews.[2] (Noelker, Ejaz, Schur, 2000). For a variety of reasons, in-person interviewing seems the only desirable mode for interviewing nursing home residents. Both mail and telephone interviewing are fraught with even more practical difficulties than face-to-face interviewing. Cognitive and mental health problems would be more problematic for interviewing in these modes than face to face. Many residents have sensory limitations (hearing or sight) that would impair their ability to respond in writing or over the telephone, and many have motor limitations that would make responding on a mail survey difficult or impossible. Identifying and screening a sample and then ensuring that only the sampled residents were interviewed would all be more problematic in either a mail or telephone survey than face to face. In some homes, few if any residents have their own telephones.

The literature is much more varied on mode of interview for surveys of nursing home residents' family members. Several authors (e.g., Lavizzo-Mourey et al., 1992; Potter, 1989) describe telephone surveys of next of kin or other proxy respondents. Looman et al. (1997) describe a survey of family members of nursing home residents with dementia conducted in the Cleveland, Ohio, area, with interviews conducted in person. The survey asked about family members' perceptions of the nursing staff. Byers (1991) describes a self-administered survey of family members of nursing home residents with Alzheimer's disease, asking about satisfaction with care. Williams (1992) discusses a telephone survey of

[2] In contrast, Ohio nursing facilities that surveyed short stay residents about post-acute care often used mail and telephone formats.

family members asking about their relatives' participation in research. None of these studies includes a comparison of different modes of interviewing for nursing home residents' next of kin, however.

Clear evidence guiding the selection between telephone and mail modes is more limited. One concern is that because families are less direct consumers, they will not be as motivated to respond to mail surveys. On the other hand, mail surveys generally have lower cost and may provide greater anonymity enabling families to express dissatisfaction more effectively. Early studies of health care satisfaction support mail over telephone mode because it minimized "socially desirable" response patterns and was thought to provide better assurance of confidentiality. However, a CAHPS study of consumers found response quality was comparable between telephone and mail modes but that response rates were lower with the mail mode, enhancing our concern about response rates (Fowler et al., 1999). Gillis and Doordan (1989) advocate the use of telephone over mail and interview mode because it is cheaper and yielded less "socially desirable" response patterns than in-person interviews and had better response and completion rates than postal mode.

Finally, for interviews of short-stay nursing home residents, in-person interviews may not be practical. Almost by definition, short-stay residents would have to be interviewed outside of the facility from which they were selected. Such interviews would be most like followup surveys of hospital patients, a number of which are described in the literature. For example, Gillis and Doordan (1989) compared mail and telephone followup of heart surgery patients. They found the data comparable between the two modes and response rates higher by telephone. Victor (1988) reported acceptable response rates (81 percent) and reliability of response (high rates of agreement when the survey was re-administered to a subsample). Korner-Bitensky et al (1994), cited earlier, found little difference between telephone and in-person interviews in a followup of rehabilitation patients.

Interviewing Cognitively Impaired Residents

As described in the section *Use of Cognitive Screens*, the literature is varied on how to screen residents for interviewability. Some researchers recommending more inclusive selection, as cited below, have developed techniques for obtaining survey responses from residents with some cognitive impairment or other limitation that may on the surface make their participation in a survey appear doubtful.

Cognitively impaired residents may be more able to complete an interview on some days than on others. Thus, repeated contacts on different days may be an appropriate strategy (Rapp, Topps-Uriri, Beck, 1994; van Maris et al., 1996a).

Uman et al. (2000) report that four key factors determine whether satisfaction information may be obtained from cognitively impaired nursing home residents: interviewer selection, interviewer training and supervision, resident selection, and interview techniques. The first three of these are discussed under the relevant headings. Table 2 summarizes Uman et al.'s recommended techniques for interviewing the cognitively impaired. (See Clark, 1994, for "manipulate the environment" section.) These techniques are very similar to strategies suggested by Bloom et al. (1971) to help interviewers compensate for the kinds of limitations many nursing home residents have: limitations in hearing and vision, language function, mobility, or balance, and limitations due to pain, fatigability, emotionality, or problems in mentation.

West et al. (1991) point out that nursing home residents often present a “flat affect,” that is, they do not express themselves through varying facial expressions, eye movements, or other nonverbal actions that interviewers are used to interpreting along with verbal responses.

If cognitively or otherwise impaired residents are to be included in nursing home satisfaction surveys, the survey design must deal with the issue of obtaining informed consent. Reich (1978) and others have pointed out that many nursing home residents are especially vulnerable, that standard techniques of obtaining informed consent may not apply to some residents, and that proxy consent is problematic for a variety of reasons.

Table 2

Recommended Techniques to Interview the Cognitively Impaired (Uman et al., 2000)

Purpose	Technique
Gain the resident's attention.	Approach slowly. Be visible when approaching. Establish and maintain eye contact. Prepare the resident for what you will talk about whenever possible. Use common gestures and facial expressions when appropriate. Use the resident's name often to gain or redirect attention. Be pleasant and smile.
Manipulate the environment.	Face resident, 2 - 3 feet away. Check whether hearing aids are working. Offer use of amplification device for unaided residents with hearing loss. Check for "extras" to enhance communication; glasses, dentures, adaptive devices, or personal items. Make sure light is on your face. Avoid glare on your face or the resident's face. Speak with the resident at eye level. Look at the resident when you speak. Place resident away from open doors where there is visible traffic. Minimize background noise—turn off TV and radios.
Articulate clearly.	Choose familiar, common words. Use low-pitched speech, without exaggeration. Use alternative phrases to convey

	meaning.
Compensate for cognitive losses.	Use short, concrete sentences. Request yes/no answers. Use one-step questions; avoid conditional phrases and clauses. Give extra time for processing and responding, using silence and pauses. Avoid questions about the timing or duration of events.

Selection and Training of Interviewers

Van Maris et al. (1996a) report using volunteers as interviewers in a resident satisfaction survey in a large Canadian tertiary care facility. They trained the volunteers for 2 days (content described in another article). In an effort to ameliorate interviewers' frustrations at locating and contacting cognitively impaired residents, this study had interviewer meetings in which they could share experiences with each other and with researchers. Uman et al. (2000) also used volunteers as interviewers. The association of for-profit nursing facilities in Ohio expects facilities to recruit volunteers to administer their survey (Noelker, Ejaz, Schur, 2000). Most research studies reported in the literature tend to use research-trained nurses or trained research assistants to conduct interviews with residents (Simmons interview, 2000; Berlowitz, 1995; Bray et al., 1995; Grau, Chandler, Saunders, 1995; Levin et al., 1986).

Uman et al. (2000) identify the following desirable personal characteristics for interviewers of nursing home residents:

- Interest in older people;
- Willingness to suspend disbelief;
- Understanding that the interviewer's role is to obtain responses from each sampled resident;
- "A positive energy" manifested in facial expressions and speech inflection; and
- Willingness to administer a structured interview.

Fowler and Mangione (1990) make a strong case that interviewers need substantial training to conduct standardized interviews with appropriate technique. In particular, the training should include supervised practice. Poorly trained interviewers are less likely to read questions as they are written, probe incomplete or unclear responses appropriately, or record responses accurately than those with more training. Poor interviewing technique in turn can result in poor data quality.

Uman et al. (1999) describe training for interviewers who will be surveying cognitively impaired residents. In addition to standard survey training techniques, such as practice with standardized reading of questions and tape recording interviews, they recommend practice and feedback in interviewing residents displaying a variety of behaviors, under the mentorship of an experienced interviewer. They also describe using a "hearing test" to demonstrate to interviewers the difficulties respondents with a range of hearing loss may have. In addition, studies emphasize continued training of interviewers while they are in the field collecting data, so that they may share experiences in interviews or make necessary adjustments to survey protocol (Uman, 2000, van Maris et al., 1996b).

QUESTION FORMAT

Responding to survey questions requires the respondent to solve a number of tasks: they need to interpret the question to understand its meaning; they then have to recall relevant instances from memory; and finally, they need to provide their response, and their response has to fit the response alternatives provided as part of the question (Schwartz, 1999). While this is a task the young and cognitively intact respondents perform with ease, the task gets difficult and taxing for the elderly and cognitively impaired. Issues related to comprehending the spoken word, as well as complexity of response scales, have to be considered while designing a nursing home resident survey.

Question comprehension. Question comprehension goes beyond reading level and whether the questionnaire is at a sixth-grade level or a third-grade level. Question comprehension is a function of the semantic understanding of the utterance, how respondents interpret the intended meaning of the question, the content of the preceding questions, and the formal features of the entire questionnaire (Clark and Schober, 1992; Grice, 1975; Schwartz, 1999). While question context affects the respondents response, this assumes that the respondent remembers the preceding question. The amount of information that can be stored and processed simultaneously at a point in time, that is *working memory*[3] *capacity*, has been found to be significantly smaller for older people than for younger people (Knauper, 1999). Biological processes that accompany normal aging causes this decline, which results in text comprehension problems and problems in learning and reasoning (see Knauper, 1999 for comprehensive review).

The other aspect of comprehension is the comprehension of the spoken word and the rate at which the interviewer asks a question. Successful comprehension requires that the respondent can understand the utterance and interpret its meaning when the speech is arriving at the rate of 2.3 to 3.00 words per second, which is the average speed of speech (Wingfield, 1999). While designing a questionnaire, the issue of comprehension affects question wording, use of reference periods, and the response scale.

- **Question wording.** When questions are worded using short sentences with reasonably simple syntax, their comprehension and recall among the elderly is generally quite good. As the length and/or syntactic complexity increases older people have more difficulty comprehending than the young (Wingfield, 1999). For interviewing the cognitively impaired, Uman et al. (2000) suggest using short, concrete sentences and one-step questions with no conditional phrases. However, if the question wording is kept simple and short for the benefit of the cognitively impaired, the same techniques can be applied with success to other cognitively intact residents of nursing homes.
- **Language Clarity.** In order to improve comprehension there should be one possible "word boundary" interpretation. The question wording should avoid oronyms[4] (e.g., "stuffy nose"

[3] "Working memory" refers to the ability to simultaneously process and elaborate new incoming information while executing rehearsal or storage processes on earlier endoded information.

[4] An oronym occurs when an acoustic stream has more than one possible word boundary.

versus "stuff he knows"). It is, therefore, important to use simple, familiar, and common words that are easy to hear and understand (Uman, 2000).

- **Reference periods.** Another aspect of questionnaire design, use of reference periods can be a challenge while interviewing nursing home residents. For questions where the respondent is asked to respond keeping in mind a reference period like in the last 10 days, or in the last 30 days, the older respondent may respond without giving serious thought to the reference period (Schechter et al., 1999). They are unable to make the connection between the reference period and the question and, hence, find it easier to ignore the reference period. Uman et al. have also suggested avoiding questions about timing or duration of events.

- **Response scale.** The order in which response alternatives are presented in a list can profoundly affect reports of attitudes as well as behaviors. This effect is present even when there are a small number of response alternatives (see Knauper, 1999, for a review). One of the seminal works in this area is by Schwartz et al. (1992) who have propounded the *cognitive elaboration model.* When a question and response scale is presented to the respondent, he/she has to think about the implications of the content of the response alternatives. This results in a complex interaction of three things: the *serial position* of the responses; the mode in which it is presented-visual or auditory or combined; and the *plausibility of the response alternatives*—does it elicit agreeing or disagreeing thoughts. This complex interaction results in either a *primacy effects*, when respondents endorse the response alternative displayed at or near the beginning of the list) or as recency effects, where the respondent pays attention to the alternatives presented late in the list. Recency effects are more prevalent in the visual format, while *primary effects* are more prevalent in interviewer administered questionnaires.

  Another compelling theory is the "satisficing theory" borrowed from Simon's (1957) economic theory of how people make economic decisions (see Bishop, 1997, for review). According to this theory, respondents answer survey questions by choosing the first satisfactory or acceptable response than take the time to evaluate all the responses posed to them.

  Answering questions with response alternatives requires the simultaneous storage, retrieval, organization, elaboration, evaluation, and manipulation of information (Knauper, 1999). These are the processes that are assumed to operate in the working memory model. The less working memory capacity an individual has available, the less he/she will be able to process, evaluate, and elaborate the information presented. There is bound to be either a recency or primacy effect if the response scale is too long and complex. In addition, respondents low in cognitive capacity more often provide a "don't know" response and use heuristic strategies rather than exhaustive memory search strategies to respond to complex questions (Knauper, 1999), or they ignore the response scale provide narrative answers than respond within the format specified by the question.

  To get around the response order effect, Uman et al. (2000) propound the use of yes/no responses. Since some questions cannot be placed in a yes/no context, they also recommend asking questions about observable events. This eliminates the need for long response scales and allows for easy question comprehension. However, there are domains and topics where

the resident may need to elaborate. Zinn et al. (1993) believe that respondents are more likely to elaborate on a response if they are asked a yes/no question first. The yes/no format helps them focus on the particular aspect of patient care they are being asked to elaborate on.

To summarize the literature on question format:

- Use short sentences so even residents with failing working memeory capacity can remember the entire statement.
- Avoid use of conditional phrases.
- Use simple syntax.
- Use simple words that are easy to understand and hear.
- Limit or do not use reference periods.
- Use short or yes/no response scales.

RESPONSE RATES

Nursing Home Cooperation

Nursing facilities may be reluctant to participate in any type of survey or research if administrators and staff are apprehensive about how the findings will be used or the potential costs to the nursing facility, particularly in terms of increased burden on staff (Ouslander, Schnelle, 1993; Franzi, Weiler, 1992; Potter, 1998). Thus, a thoughtfully designed effort and a commitment from staff, particularly administrative staff, is important if the results of a nursing facility survey are to be useful (Ejaz, 2000; Ouslander, Schnelle, 1993). In this section, we review what is known about nursing facility participation rates and the research on correlates of participation in health surveys and consider strategies that can be used to gain cooperation.

While interest in consumer satisfaction surveys is clearly growing in all areas of health care, nursing facility participation has generally lagged behind that of hospitals and other health care providers. One notable exception is Ohio where a study on the prevalence of satisfaction surveys and the general level of satisfaction with them found that 79 percent of the surveyed facilities conducted satisfaction surveys, usually of both residents and families.[5] Seventy percent of the facilities surveyed only cognitively alert residents. Ninety-eight percent of the facilities reported that their primary reason for conducting these surveys was for quality improvement. Nursing facilities indicated that they were only moderately pleased with the satisfaction survey process. The two problems cited most frequently were low response rates (34% of the facilities) and inadequate quality of information (25% of facilities) from the survey (Noelker, Ejaz, Schur, 2000).

Generally, nursing facility willingness to participate in survey efforts is greatest for federally supported national surveys that typically collect data on a very small number of residents in the facility. Potter (1997a; 1997b; 2000) examined the correlates of nonresponse in several of the recent more general national nursing facility surveys, including the 1985 National Nursing Home Survey (nonparticipation rate—7%), the 1987 National Medical Expenditure Survey (nonparticipation rate—5%), the 1991 National Medical Expenditure Survey- Feasibility Study (nonparticipation rate—17%), the 1995 National Nursing Home Survey (nonparticipation rate—3%), the 1995 Medical Expenditure Panel Survey Nursing Home Component (NHC) Pretest (nonparticipation rate—24%) and the 1996 Medical Expenditure Panel Survey NHC (nonparticipation rate—15%). She concludes that data collection burden (which was quite different for the NNHS in comparison to the NMES and the MEPS NHC) can have a deleterious effect on willingness to participate and that response rates for surveys with comparable burden have declined over time (especially since full implementation of OBRA 1987 regulations).

---

[5] There the association of for-profit homes offers satisfaction survey services to its membership twice a year at no cost and has done so for the past two years. The survey is a one page, 21item form that is delivered in bulk to each participating facility. The facility is responsible for screening residents using the MDS, recruiting and overseeing volunteers to assist residents in completing the forms and for mailing the form out to residents' families. Between 28 and 35 percent of member facilities use these services.

Potter (1988; 2000) found that significant predictors of nonresponse were for-profit ownership, location in the South, and Medicaid reimbursement method. Significant predicators of agreement included having state and national nursing facility association endorsement and interviewer characteristics (male, older, college, non-white, experience in a medical environment). In a model that excluded interviewer characteristics, being in an area with a large supply of nursing facility beds per population aged 75 years or older and a lower supply of hospital beds per capita were also predictors of non-response.

The 1991 Health Provider Inventory (HPI) surveyed some 73,801 nursing and personal care homes and facilities for the mentally retarded. Using a mail survey with in-person followup of a sample of nonrespondents, the HPI successfully classified 78.6 percent of facilities, either as not in scope or according to survey information (Sommers, 1993). Sommers attributes the relatively low response rate to inclusion of a large number of small facilities and a lack of funds for followup. The 1986 Inventory of Long-Term Care Places (ILTCP), a similar effort, successfully classified more than 97 percent of facilities.

In a random sample of Wisconsin nursing facilities, 54 percent agreed to participate in a study of medication use. Greater financial resources (higher SNF per diems) and better performance histories (fewer medication violations) were associated with a greater likelihood of participation (Mount, 1992). The latter raises the issue of generalizability when participation is voluntary. Others have also raised the concern that satisfaction surveys that rely on voluntary participation may attract only nursing facilities that expect to perform well, noting that mandatory participation may be required to obtain representative performance information.

Ouslander and Schnelle (1993) suggest that participation rates will be higher with (1) a well-piloted, scientifically sound study design; (2) reimbursement of staff for all types of study assistance; (3) provision of feedback and findings to the facility; and, (4) research findings that are useful for quality assurance efforts. Ensuring that staff understand the purpose of the survey and will not be threatened by its findings, will promote a positive attitude and may encourage resident cooperation. Ejaz (2000) notes that nursing homes may find that participation in satisfaction surveys can be used for quality assurance and in competing for managed care contracts.

Resident Cooperation

Once the nursing facility administrators have agreed to a satisfaction survey, resident cooperation must be obtained. While some families and others express ethical concerns about conducting research in nursing homes (Annas, Glantz, 1986; Warren et al., 1986; Williams, 1992), it is possible to obtain good response rates from nursing facility residents. Uman (2000) reports that 16 percent of residents refused to complete her nursing facility satisfaction survey; an additional 8 percent of residents failed her minimal cognitive screen. Zinn, Lavisso-Mourey, and Taylor (1993) report that 15 percent of the residents eligible for their satisfaction survey declined to participate. Van Maris et al. (1996b) report that 46 percent of the sampled residents were unable to complete the satisfaction interview, including those who were unresponsive, had died or could not be located, refused, were too ill, terminated the interview or failed to complete it for some other reason. Among Ohio nursing facilities, reported response rates for residents averaged 60 percent (Noelker, Ejaz, Schur, 2000). Generally, participation rates in nursing facility clinical intervention studies is approximately 50 percent (Ouslander, Schnelle, 1993). An empirical study of resident participation rates in a nursing facility medication study found that stable facility ownership and lower administrative turnover were associated with higher resident response rates (Mount, 1992). In administering the RSI to residents in three nursing homes, Simmons et al. (1997) reported that 257 of 274 (93.8%) of sampled residents were able to be contacted; the other 17 were discharged, hospitalized, transferred, deceased, or involved in very time-consuming medical treatments. There was no a priori screening. Of the 257 residents, 202 (78.6%) passed a minimal screening interview and agreed to be interviewed. (The citation does not distinguish between those who failed the screening and those who refused to be interviewed.)

Repeated contacts on different days may be appropriate for cognitively impaired residents who have “bad days” (Rapp, Topps-Uriri, and Beck, 1994), The same strategy may be appropriate for depressed residents or those with other behavioral/emotional conditions.

Staff Cooperation

Nursing facility satisfaction surveys have generally not included facility staff as proxy respondents for residents. The potential conflict of interest may make this inappropriate. However, employee satisfaction among nursing facility staff may, in itself, be an important correlate of resident satisfaction. Cohen-Mansfield and Noelker, (2000) pose a model of nursing facility staff satisfaction and stress. In their model, staff satisfaction and stress are expected to influence patient care and consequently may also affect resident satisfaction. Vital Research’s Resident Experience and Assessment of Life (REAL) system includes an employee satisfaction survey and posits that employee satisfaction will influence resident satisfaction.

Several investigators point out the importance of staff awareness and support for the research effort (Ouslander, Schnelle, 1993; van Maris et al., 1996b). Other investigators suggest that strategies to enhance staff cooperation in clinical intervention studies in nursing facilities include minimizing disruptions of residents and staff members routines, orienting all shifts to the presence of the research activity, finding a supportive staff member to act as a paid consultant, offering empathy to harried staff and giving positive feedback for assistance (Eisch et al., 1991). Too much staff involvement, on the other hand, may compromise resident anonymity and possibly influence resident responses.

Family and Significant Others Cooperation

Cooperation and participation of family and friends varies markedly from study to study. The Ohio survey reported that family response rates averaged 45 percent across responding nursing facilities (Noelker, Ejaz, Schur 2000). Higher response rates were obtained in a Canadian nursing facility family satisfaction survey because it used an initial telephone contact to confirm address information and alert families that the survey was soon to be mailed. This yielded a 69 percent response rate for the 89 percent of residents identifying a family member or frequently visiting friend (van Maris et al., 1996a). Lavisso-Mourey, Zinn, Taylor, 1992, report a response rate of 90 percent for a telephone survey of family and friends. The latter is deceptively high as having a family member or friend available to participate was an initial requirement for resident participation in the study.

Potter (1989) described response patterns to next-of-kin interviews from the 1987 NMES IPC. Of sample persons with a completed baseline questionnaire in the nursing home, next-of-kin interviews were completed for 76 percent. About half of the nonresponse was failure to identify an eligible next of kin; the other half represented failure to complete an interview with an identified next of kin. Men and nonwhite residents were more likely to have no next of kin identified, as were residents of noncertified facilities and of facilities in metropolitan areas. Next-of-kin nonresponse was higher for sample persons with no limitations in activities of daily living, with no living siblings, who had never married, were black, or were residents of noncertified facilities in metropolitan areas.

Item Nonresponse

Rakowski, Mor, and Hiris (1994) suggest that item nonresponse (particularly "Don't know" responses) may in some situations be useful data. Using data from the National Longitudinal Study on Aging, they found that "NR/DK responses by older adults to some self-report questions about health status convey meaningful information relative to subsequent mortality."

After analysis of nonresponse to health and functional status and satisfaction questions in a survey of postoperative patients, Guadognoli and Cleary (1992) conclude among survey participants, "a high proportion of elderly and sick respondents will not respond to at least some items." They recommend using multiple-item scales to ameliorate the effects of item nonresponse and designing questions that are salient to the population being studied and easily understood by respondents with a wide range of education.

CONCLUDING NOTE

While a number of approaches to measuring quality of nursing home care have been described in the literature, there appears to be a growing consensus about some key methodological issues. First, the consumer perspective is important and worth measuring. While residents are the primary consumers, family members and significant others are important consumers as well. Second, the perspectives of these two groups are different; family members' opinions cannot be substituted for residents' opinions. Although survey nonresponse due to cognitive, physical, or emotional limitations may be substantial, the resulting potential for nonresponse bias cannot be offset by using proxy respondents, whether family members or staff. Ideally, both perspectives should be measured. Third, while some residents will be unable to respond to any kind of survey in an interpretable way, well-designed survey questions and data collection methods may yield useful responses from mildly and moderately impaired residents. Finally, long-term residents of nursing homes must be interviewed in person, while family members may be interviewed by mail, telephone, or in person

APPENDIX A

EXCERPT FROM ITEM POOL

Domain Item	*Response Scale*	*Reference*
Admissions		
Overall, how is the facility doing at helping you find and move into a good nursing facility?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
What do you like best about the admissions and move-in process?	Open ended	Hebrew Home of Greater Washington, Resident Questionnaire
What did you like least about the admissions and move-in process?	Open ended	Hebrew Home of Greater Washington, Resident Questionnaire
Overall, how is the facility doing at providing you with good advice and assistance when choosing and moving into the facility?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing at helping you know the forms and procedures required to leave the nursing facility if wanted?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Autonomy and Choice		
Overall, how is the facility doing in helping you be as independent as your health will allow?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in helping you continue to be productive, even though sight and hearing are declining?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in respecting your rights and privacy?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in moving you to another room only with your permission?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Communication		
Overall, how is the facility doing in providing you help with unhappiness?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in providing you help with loneliness?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
How satisfied are you with the Hebrew Home staff on staff's listening skills?	On a scale of 1 to 7 where 1 is Not at all Satisfied and 7 is Extremely Satisfied	Hebrew Home of Greater Washington, Resident Questionnaire

APPENDIX A. EXCERPT FROM ITEM POOL (continued)

Domain Item	*Response Scale*	*Reference*
Courtesy and Respect		
Overall, how is the facility doing in providing staff who never treat you like a child and do not threaten with mental or physical abuse?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Do the nurses treat you well?	Yes/No	Zinn, et al., Nursing Home Resident Satisfaction Survey
How well do they (nurses) treat you?	Very Good, Good, OK, Not so Good	Zinn, et al., Nursing Home Resident Satisfaction Survey
Do the doctors treat you well	Yes/No	Zinn, et al., Nursing Home Resident Satisfaction Survey
How well do they (doctors) treat you?	Very Good, Good, OK, Not so Good	Zinn, et al., Nursing Home Resident Satisfaction Survey
Overall, how is the facility doing in not criticizing you after bathroom accidents?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in respecting your ability to carry on a meaningful conversation?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in providing staff who do things for your convenience, not their own?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Environment		
Overall, how is the facility doing in providing quiet, especially at night (no loud staff talk, slamming doors, etc.)?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
How satisfied are you with the overall atmosphere and environment of the Hebrew Home?	On a scale of 1 to 7 where 1 is Not at all Satisfied and 7 is Extremely Satisfied	Hebrew Home of Greater Washington, Resident Questionnaire
Do you get enough quiet and privacy?	Yes/No	Zinn, et al., Nursing Home Resident Satisfaction Survey
Overall, how is the facility doing in providing bright and cheery colors in halls and common areas?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
How satisfied are you with the cleanliness and maintenance services at the Hebrew Home?	On a scale of 1 to 7 where 1 is Not at all Satisfied) and 7 is	Hebrew Home of Greater Washington, Resident Questionnaire

	Extremely Satisfied	

APPENDIX A. EXCERPT FROM ITEM POOL (continued)

Domain Item	*Response Scale*	*Reference*
Family and Community		
Overall, how is the facility doing in helping you meet and get to know other residents?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in helping you continue to be an important and contributing member of your family and community?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in helping you maintain your friendships in the community?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in helping your family know with it is like to be in a nursing home?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in helping you have your family members visit you frequently?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Food Services		
Overall, how is the facility doing in providing good meals that meet your taste and dietary needs, and that are served in a pleasant setting?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in providing tasty meals even if you are on a special diet?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Do you enjoy mealtime (presentation, service, choice, taste)?	Yes/No	Zinn, et al., Nursing Home Resident Satisfaction Survey
How would you rate mealtime?	Very Good, Good, OK, Not so Good	Zinn, et al., Nursing Home Resident Satisfaction Survey
How satisfied are you with the food services at the Hebrew Home?	On a scale of 1 to 7 where 1 is Not at all Satisfied) and 7 is Extremely Satisfied	Hebrew Home of Greater Washington, Resident Questionnaire

APPENDIX A. EXCERPT FROM ITEM POOL (continued)

Domain Item	*Response Scale*	*Reference*
Medical Services		
How satisfied are you with the Speech therapy your receive on an overall basis?	On a scale of 1 to 7 where 1 is Not at all Satisfied and 7 is Extremely Satisfied	Hebrew Home of Greater Washington, Resident Questionnaire
Overall, how is the facility doing in providing you with quality medical care from your doctor when needed?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Do the doctors come quickly when you ask to see them?	Yes/No	Zinn, et al., Nursing Home Resident Satisfaction Survey
How would you rate the time it takes (the doctors) to come see you?	Very God, Good, OK, Not so Good	Zinn, et al., Nursing Home Resident Satisfaction Survey
Overall, how is the facility doing in understanding, monitoring, and meeting your medical needs?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact) Satisfaction Survey
Overall, how is the facility doing in helping you not stay in a wheelchair too long?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact) Satisfaction Survey
Overall, how is the facility doing in helping you have daily physical therapy so that you do not regress or weaken?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Nursing Services		
Overall, how is the facility doing in providing staff who see their role as "more than a job"?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
How satisfied are you with the Hebrew Home staff on responsiveness to your questions and concerns?	On a scale of 1 to 7 where 1 is Not at all Satisfied) and 7 is Extremely Satisfied	Hebrew Home of Greater Washington, Resident Questionnaire
Overall, how is the facility doing in providing staff who know what it is like to be old?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact) Resident Questionnaire
Overall, how is the facility doing in providing you with high-quality staff who know your needs and make every attempt to fulfill those needs?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
How satisfied are you with the nursing care your receive on an overall basis?	On a scale of 1 to 7 where 1 is Not at all Satisfied and 7 is	Hebrew Home of Greater Washington, Resident Questionnaire

	Extremely Satisfied	

APPENDIX A. EXCERPT FROM ITEM POOL (continued)

Domain Item	*Response Scale*	*Reference*
Program Services		
How would you rate the daily schedule?	Very God, Good, OK, Not so Good	Zinn, et al., Nursing Home Resident Satisfaction Survey
Overall, how is the facility doing in having programs that are not demeaning or childlike?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in offering church services that you can hear and are in a religious atmosphere?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in making available interesting and useful programs?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Safety and Security		
Overall, how is the facility doing in having plenty of staff on duty during weekdays and weekends?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in keeping your possessions safe and taking action when theft occurs?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Overall, how is the facility doing in helping you feel safe and secure in your room and in the nursing home?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Global Satisfaction		
Considering all your experience with the facility, how would you rate the quality of the job the facility is doing?	Excellent, Very Good, Good, Fair, Poor	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Thinking about aspects of the care you received in the past 6 months, how satisfied are you with the Hebrew Home overall?	On a scale of 1 to 7 where 1 is Not at all Satisfied and 7 is Extremely Satisfied	Hebrew Home of Greater Washington, Resident Questionnaire
Given the opportunity to choose a nursing facility again, how likely would it be that you would choose this nursing home?	Very Likely, Likely, Somewhat Likely, Unlikely, Very Unlikely	AHCA, Satisfaction Assessment Questionnaire (Cognitively Intact)
Considering everything, how would you rate overall satisfaction (doctor, nursing care facilities, etc.)	Very Good, Good, OK, Not so Good	Zinn, et al., Nursing Home Resident Satisfaction Survey

APPENDIX B

SURVEY TABLE

Survey	Developed by	Mode	Respondent	Survey Domains	Response Scale	Sampling	Cognitive Screens	Length
American Health Care Association (AHCA), Satisfaction Assessment Questionnaire (Cognitively intact, family members of residents with mild dementia, and family members of cognitively intact residents), 1994 **<u>Used By</u>** Not Known	Gallup and Gustafson & Associates	In-person for residents and by mail for family members	Cognitively intact nursing facility residents	*For cognitively intact residents* Family and community involvement Independence and respect Programs Facility and setting Meals and dining Health care/Doctor's care Nursing staff Safety and security Roommates and other residents Moving in/Out of the facility Global satisfaction *For family members of residents with mild dementia* Family adaptation Family, fiends and community Independence and respect Nursing facility program Nursing facility setting Meals and dining Health care/Doctor's care Nursing staff Toileting Nursing facility management Safety and security Relationship with other residents Moving in/out survey Death issues Global satisfaction *For family members of cognitively intact residents* Family adaptation Resident adaptation Community involvement	Excellent, Very Good, Good, Fair, Poor	2,500 facilities/300 cognitively intact residents, 300 family members of residents with mild dementia, and 300 family members of cognitively intact residents	Not Known	100+ questions for 15 surveys outlined in "content"

Survey	Developed by	Mode	Respondent	Survey Domains	Response Scale	Sampling	Cognitive Screens	Length
				Independence and respect Nursing facility programs Health care/Doctor care Toileting				

APPENDIX B. SURVEY TABLE (continued)

Survey	Developed by	Mode	Respondent	Survey Domains	Response Scale	Sampling	Cognitive Screens	Length
AHCA (cont..)				Nursing staff Nursing facility management Safety and security Relationship with others residents Moving in/out of nursing facility Meals and dining Global satisfaction				
Hebrew Home of Greater Washington, Resident and Family Member Questionnaire **Used By:** Hebrew Home of Greater Washington	Shugoll Research	In-person for residents and by phone for family members	Cognitively intact residents and family members or legal guardians of residents	*For residents* Admissions and move-in process Atmosphere and environment On-staff physician Nursing care Social services Food services Activities Cleanliness and maintenance Global satisfaction *For family members* Admissions and move-in process Atmosphere and environment On-staff physicians Nursing care Food services Activities Cleanliness and maintenance Discharge planning Interaction with staff Global satisfaction	8 point Satisfaction scale: where 1 is *Not At All Satisfied* and 8 is *Extremely Satisfied;* , 8 point Important scale: where 1 is *Not At All Important* and 8 is *Extremely Important;* Yes/No	72 cognitively intact residents and family members of 558 current residents and those recently discharged (achieved a 56% response rate)	Staff determined if intact (informally)	Resident survey has 39 items and family member survey has 43 questions
Challiner, et al., Quality of Long-Term Institutional Care Survey, 1994 **Used By**: Pilot Study	Polytechnic of North London, School of Applied Social Studies and Sociology	Mail	Nursing home administrators and follow-up interviews with the administrator using the original long 59-item questionnaire and two nursing	Environment services Autonomy and choice Toileting Privacy Safety and security Staff interaction	Yes/No	216 nursing homes	None	18 items

			staff using the short 18-item questionnaire					

APPENDIX B. SURVEY TABLE (continued)

Survey	Developed by	Mode	Respondent	Survey Domains	Response Scale	Sampling	Cognitive Screens	Length
Kruzich, Nursing Home Satisfaction Scale, 1992 **Used By** Not Known	Jean Kruzich	In-person interview	Residents	Food Cleanliness Autonomy and choice Nursing care Medical services Privacy Activities Staff interaction Safety and security	Agree, Neutral, Disagree	Not Known	Not Known	17 questions
The Benjamin Rose Institute, 1997 Kethley House Family Satisfaction Survey **Used By:** The Benjamin Rose Institute	The Margaret Blenkner Research Center, The Benjamin Rose Institute	In-person for residents and by mail for family members	Residents, family member or legal guardian (for long term and short term rehab. residents)	Admitting process Nursing care Social services Dietary services Laundry services Therapy Activities Medical and ancillary services Office management Environment [For short term rehab, all of the above except Laundry services; But include Discharge planning]	No Improvement Needed, Some Improvement Needed, Great Deal of Improvement Needed	Only cognitively intact residents which is ~20 percent of long term care residents. And family members of ALL residents.	Determined by Staff	44 questions
Zinn, et al., Nursing Home Resident Satisfaction Survey, 1993 **Used By:** Not Known	Zinn, Lavizzo-Mourey and Taylor, supported by a grant from Robert Wood Johnson Foundation	In-person interviews	Nursing home residents	Physician and nursing services Reliability Technical skills Environment Global satisfaction	Very good, Good, OK, Not so good	Four nursing homes, in the Philadelphia area, 198 eligible residents; 85% response rate	If residents were able to respond orally and in English	11 items
Manor Healthcare **Used By:**	Independent research firm	Mail	Family member or legal guardian	Overall satisfaction, Environment Nursing care Food services Activities	0-10 Not satisfied to extremely satisfied scale	Not Known	Not Known	34 items

Nursing Homes in the Manor Care chain				Laundry Billing				

APPENDIX B. SURVEY TABLE (continued)

Survey	Developed by	Mode	Respondent	Survey Domains	Response Scale	Sampling	Cognitive Screens	Length
State of Florida, Long-Term Resident Satisfaction Survey, Short-Term Resident Satisfaction Survey, and Family or Guardian Survey, 1999 **<u>Used By</u>** Proposed to be used by Florida Agency for Health Care Administration for a state-wide survey	Florida Agency for Health Care Administration	In-person interviews with nursing home residents, and mail for family members of residents	Resident, family member or legal guardian	*For long-term survey* Autonomy and choice Enjoyable activities Safety and security Cleanliness Food services Laundry services Staff responsiveness Staff friendliness/kindness Medical and therapy services *For short-term survey* Autonomy and choice Comfort Staff responsiveness Staff friendliness/kindness Therapy services *For family or guardian* Autonomy and choice Respect and dignity Comfort Privacy Staff responsiveness Staff friendliness/kindness *Cognitive screen* Object identification Self-identification (e.g., first and last name, DOB, where live now) Short-term memory	Always, Most of the Time, Some of the Time, Never	In each facility 20 long-term residents (resided in the nursing home for at least 3 weeks) and 10 short-term residents	A five-question screener administer the long-term residents satisfaction survey only to those respondents who cleared the cognitive screen	13 items in long-term, 6 in the short-term and 11 in the family survey
National Research Corporation, Nursing Care Facility Resident Satisfaction Survey **<u>Used By:</u>**	National Research Corporation	Mail	Resident	Admission and administration Dining services Doctor and other medical professionals Environment Nurses Nursing assistants Social services	Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree; Yes/No,	Not Known	Not Known	

Survey	Developed by	Mode	Respondent	Survey Domains	Response Scale	Sampling	Cognitive Screens	Length
Not Known				Global satisfactions				

APPENDIX B. SURVEY TABLE (continued)

Survey	Developed by	Mode	Respondent	Survey Domains	Response Scale	Sampling	Cognitive Screens	Length
K & K Research, Customer Satisfaction Instrument, 1994 **Used By:** Not Known	Koenig and Kleinsorge,	Mail	Resident, family members or legal guardians	Nursing assistants Staff friendliness and kindness Staff awareness of safety Staff communication Food services Cleanliness and housekeeping Safety and security Enjoyable activities Atmosphere and environment Chapel services Staff responsiveness	Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree	Not Known	Not Known	46 items
Norton et al., Long-Term Care Resident Evaluation, 1996 **Used By:** Not Known	Sunnybrook Health Science Center (SHSC), Toronto, Canada	Mail	Resident, family member or legal guardian	Autonomy Living area Food Activity Staff Dignity Global satisfaction	Excellent, Good, Fair, Poor, Terrible	12 nursing homes participated in the study; in nursing homes with fewer than 300 beds, all residents were interviewed; in larger nursing homes, a stratified random sample was drawn	None	127 for residents and 145 for family member survey
Ohio Healthcare Association **Used By:** 200 Members of OHCA-For profit nursing homes in Ohio.	Adapted the AHCA (American Health Care Association) survey	In-person for residents, by mail for family members,	Cognitively intact residents and family member of all residents	Living environment Health care Independence Food and dining Emotional support Visitors	Very satisfied, satisfied, very dissatisfied, dissatisfied, Yes/No	ALL cognitively intact residents at the time of the survey which is conducted twice a year-in March and September; and 50% percent of all family members	Use MDS data to screen for those who are cognitively aware	21 items
Resident Experience and Assessment of Life (REAL)/Resident Satisfaction Interview, 1997 **Used By:**	Vital Research with two grants from National Institutes of Health (NIH) and with endorsement from American	In-person for residents and mail for family members.	Both cognitively intact and impaired residents, and their family members	Help and assistance Communication with staff Autonomy and choice Companionship Food and environment Safety and security	Yes/No	257 nursing home residents	None	42 items

Not Known	Association of Homes and Services for the Aging (AAHSA)							

APPENDIX B. SURVEY TABLE (continued)

Survey	Developed by	Mode	Respondent	Survey Domains	Response Scale	Sampling	Cognitive Screens	Length
Davis et al. Nursing Home Service Quality Inventory, 1997 **Used By:** Not Known	Davis, Sebsatian, and Tschetter under a grant from Carroll Martin Gatton College of Business and Economics of the University of Kentucky.	In-person interviews	Nursing home residents-long-term stay	Staff and environmental responsiveness Dependability and trust Personal control Food-related services and resources	Excellent, satisfaction	In Round 1 103 residents from 23 facilities in the Bluegrass Area Development District of Kentucky were chosen. In Round 2 chose, 194 male residents from a Veterans Affairs Medical Center long-term care facility in a southeastern city.	Residents with a score lower than 22 on the Mini Mental Status Examination were dropped.	32 items
Mostyn, et al., Quality Assessment in Nursing Home Facilities: Customer Satisfaction Survey **Used By:** Not Known	Parkside Associates, Inc, Park Ridge, Ill.	Mail	Person in nursing home who could best elicit a response on behalf of the resident	Facility care and services Food services Nursing Comfort and cleanliness Facility characteristics Overall rating of 14 service related areas	Likert Scale	159 facilities from41 states, most facilities had 100 or fewer residents	None	57 items
Measures, Indicators, and Improvement of Quality of Life in Nursing Homes **Used By** Survey is still under development	Robert and Rosalie Kane, University of Minnesota; sponsored by HCFA	In-person interviews, Mail with telephone follow-up for family members	Residents of high and low cognitive ability according to MDS (facility determined) and Family members	Dignity, Autonomy/Choice Individuality Privacy (i.e. sense of privacy) Enjoyment Meaningful activity Relationships Comfort Sense of security/order Spiritual well-being Functional competence Overall satisfaction ratings [*Family member questionnaire* includes all of the above except Relationship and Spiritual-well-being items. Additional questions related to the family member as a consumer were included.]	Likert Scale, and Y/N for residents of low cognitive ability	2000 residents in 40 nursing homes in 5 states. Equal numbers of high and low cognitive ability across facilities are sampled.	Facility determines cognitive ability by MDS. Screener is administered to determine if resident answer the more complex Likert scale questions. If not the Y/N scale is used/	140 items

APPENDIX B. SURVEY TABLE (continued)

Survey	Developed by	Mode	Respondent	Survey Domains	Response Scale	Sampling	Cognitive Screens	Length
HealthRays Alliance **<u>Used By:</u>** 25 not-for profit nursing home in NE Ohio-members of the Alliance	Benjamin Rose Institute	In-person resident survey, mail for family member survey, mail survey for sub acute care	Cognitively Intact residents and family members	*For Long term Resident Survey* Facility Environment Food Services Nursing Assistants Nurses Medical Services Social Work Services Activities Administration Overall *For Sub-acute Care* Admission Process Facility, Environment & Transportation Food Services Nursing Care Medical Services Rehabilitation Services Social Work Services Activities Discharge Planning Administration Overall *For family members* Facility, Environment & Transportation Food Services Nursing Assistants Nurses Medical Services Social Work Services Activities Billing Communication Administration Overall	Very Good, Good, Fair, Poor	Cognitively intact residents and family members of both intact and impaired residents from 25 nursing homes. Since the survey will be conducted twice a year half the sample will be selected for each wave.	Conducted by a multi-disciplinary team of staff (to avoid bias). Some facilities might use MDS	47 items

APPENDIX C

REFERENCES

General References

Albert, S.M., Castillo-Castanada, C., Jacobs, D.M., Sano, M., Bell, K., Merchant, C., Small, S., and Stern, Y. (1999). Proxy-reported quality of life in Alzheimer's patients: Comparison of clinical and population-based samples. *Journal of Mental Health and Aging,* 5(1), 49-58.

Aller, L.J. and Van Ess Coeling, H. (1995). Quality of life: Its meaning to the long-term care resident. *Journal of Gerontological Nursing,* 20-25.

Annas, G.J., and Glantz, L.H. (1986). Rules for research in nursing homes. *N Engl J Med,* 315 (18), 1157-1158.

Anthony, J.C., Le Resche, L., Niaz U, et al. (1982). Limits of Mini-Mental State as a screening test for dementia and delirium among hospital patients. *Psychol Med,* 12, 397-408.

Aronson, M.K., Cox, D., Guastadisegni, P., Frazier, C., Sherlock, L., Grower, R., Barbera, A., Sternbert, J., Breed, J., and Koren, M.J. (1992). Dementia and the nursing home: Association with care needs. *Journal of the American Geriatrics Society*, 40, 27-33.

Bassett, S.S., Magaziner, J., and Hebel, J.R. (1990). Reliability of proxy response on mental health indices for aged, community-dwelling women. *Psychol Aging,* 5(1), 127-132.

Becker, M., Bigelow, W., and Collins, T. (1999). *Association with cognitive decline with functional status in an institutionalized population*. Florida Mental Health Institute.

Berlowitz, D.R., Du, W. Kazis, L., and Lewis, S. (1995). Health–related quality of life of nursing home residents: Differences in patient and provider perceptions. *Journal of the American Geriatrics Society*, 43, 799-802.

Binstock, R.H., Post, S.G., and Whitehouse, P.J. (1992). *Dementia and aging: Ethics, values, policy choices.* Baltimore: Johns Hopkins Press.

Bishop, G.F., Smith, A.E. (1997.) Response-order effects in public opinion surveys: The plausibility of rival hypotheses. *ASA Proceedings of the Section on Survey Research Methods.* American Statistical Association (Alexandria, VA), 1041-1046.

Bleismer, M., and Earl, P. (1993). Research considerations: Nursing home quality perceptions. *Journal of Gerentological Nursing,* 19 (6), 27-34.

Bloom, M., Duchon, E., Frires G., Hanson, H., Hurd, G. and South, V. (1971). Interviewing the ill aged. *Gerontologist,* 11(4), 292-299.

Bray, J., Powell, J., Lovelock, R., and Philp, I. (1995). Using a softer approach: Techniques for interviewing older people. *Prof Nurse,* 10 (6), 350-353.

Briscoe, M.E. (1984). Research note: Proxy responses in health surveys: a methodological issue. *Social Health Illn*, 6(3), 359-365.

Brod, M., Stewart, A.L., Sands, L., and Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The Dementia Quality of Life Instrument. *The Gerontologist*, 39(1), 25-35.

Byers, P.H. (1991). Family members perceptions of care of institutionalized patients with Alzheimer's disease. *Applied Nursing Research*, 4(3), 135-140.

Case, T. (1996). A quality assessment and improvement system for long-term care. *Quality Management in Health Care*, 4(3), 15-21.

Challiner, Y., Watson, R., Julious, S., and Philip, I. (1994). Postal survey of the quality of long-term institutional care. *International Journal of Geriatric Psychiatry*, 9(8), 619-625.

Clark, H.H., and Schober, M.F. (1992). Asking questions and influencing answers. In J.M. Tanur (Ed.), *Questions about questions,* pp.15-48. New York: Russell Sage.

Clark, W. (1994). General Principles of management. In: R.C Hamdy, J.M. Turnball, W. Clark, M.M. Lancaster (Eds). *Alzheimer's disease: A handbook for caregivers 2nd Ed.* St. Louis: Mosby.

Clipp, E.C., and Elder, G.H. (1987). Elderly confidants in geriatric assessment. *Compr Gerontol* [B], 35-40.

Cohen-Mansfield, J., and Noelkar, L. Nursing staff satisfaction in long-term care: Overview, 2000. In J. Cohen-Mansfield, F.K. Ejaz, P. Werner, et al. (Eds). *Satisfaction surveys on long-term care,* (pp. 137-165). New York: Springer Publishing Company.

Davidson, H.A., Borrie, M.J., and Crilly, R.G. (1991). Copy task performance and urinary incontinence in Alzheimer's disease. *J Am. Geriatr Soc*, 39, 467-71.

Davis, M.A., Sebastian J.G., Tschetter J. (1997). Measuring Quality of Nursing Home Service: Residents' Perspective. *Psychological Reports*, 81, 531-542.

Donabedian, A. (1988). The quality of care: How can it be assessed? *Journal of the American Medical Association*, 260(12), 1743-1748.

Dorman, P.J., Waddell, F., Slattery, J., Dennis, M., and Sandercock, P. (1997). Are proxy assessments of health status after stroke with the EuroQOL questionnaire feasible, accurate, and unbiased? *American Heart Association,* pp.1883-1887.

Doyle, G.C., Dunn, S.I., Thadani, I., and Lenihan, P. (1986). Investigating tools to aid in restorative care of Alzheimer's patients. *J Gerontol Nurs*, 12, 19-21.

Eisch, J.S., Colling, J., Ouslander, J., Hadley, B.J., and Campbell, E. (1991). Issues in implementing clinical research in nursing home settings. *Journal of the New York State Nurses Association*, 22(3).

Ejaz, F.K. (2000). An overview of the process of conducting consumer satisfaction surveys in nursing facilities. In J. Cohen-Mansfield, F.K. Ejaz, P. Werner, et al. (Eds). *Satisfaction surveys on long-term care,* (pp. 137-165). New York: Springer Publishing Company.

Epstein, A.M., Hall, J.A., Tognetti, J., Son, L.H., and Conant, L., Jr. (1989). Using proxies to evaluate quality of life. Can they provide valid information about patients' health status and satisfaction with medical care? *Med Care,* 27(3 Suppl), S91-98.

Folstein, M.F., Folstein, S.E., and McHugh, P.R. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.

Fowler, F.J., and Mangione, T.W. (1990). *Standard survey interviewing: minimizing interviewer-related error, standard survey interviewing*, Ch.7.

Fowler, F.J., Gallagher, P.M., and Nederend, S. (1999). Comparing telephone and mail responses to the CAHPS survey instrument. *Medical Care,* 37 (3) Supplement, 41-49.

Franzi, C., and Weilder, P.G. (1992). The research process in long-term care facilities. *The Journal of Long-Term Care Administration.*

Gerety, M.B., Cornell, J.E., Mulrow, C.D., Tuley, M., Hazuda, H.P., Lichtenstein, M., Aguilar, C., Kadri, A.A. and Rosenberg, J. (1994). The Sickness Impact Profile for Nursing Homes (SIP-NH). *Journal of Gerontology: Medical Sciences*, 1994, 49, 1, M2-M8.

Gilliss, C., DNSc, RNC, and Marttinen Doordan, A., MS, RN. (1989). Data gathering by telephone. *Progress in Cardiovascular Nursing,* 4.

Grant, N.K., Reimer, M., and Bannatyne, J. (1996). Indicators of quality in long-term care facilities. *Int. J Nurs Stud*, 33(5), 469-478.

Grau, L., Chandler, B., and Saunders, C. (1995). Nursing home residents' perceptions of the quality of their care. *Journal of Psychosocial Nursing*, 33(5), 34-41.

Grice, H.P. (1975). Logic and conversion, In P.Cole and J.L. Morganb (Eds.) *Syntax and semantics, Vol 3, Speech acts,* pp. 41-58. New York: Academic Press.

Grootendorst, P.V., Feeny, D.H., and Furlong, W. (1997). Does it matter whom and how you ask? Inter- and intra-rater agreement in the Ontario Health Survey. *J Clin Epidemiol*, 50(2), 127-135.

Gruber-Baldini A.L., Zimmerman, S.I., Mortimore, E., Magaziner, J. (1999). *The validity of the Minimum Data Set in measuring the cognitive impairment of nursing home admissions*. University of Maryland School of Medicine.

Guadagnoli, E., and Cleary, P.D. (1992). Age-related item nonresponse in surveys of recently discharged patients. *Journal of Gerontology: Psychological Sciences*, 47(3), P206-212.

Haase, K.W., and Wilson, R. (1972). The study design of an experiment to measure effects of using proxies resources in the National Health Interview Survey. *Proceedings of the Social Statistics Section.* American Statistical Association, pp. 289-293.

Hartmaier, S. L., Sloane, P.D., Guess, H.A., and Koch, G.G. (1994). The MDS cognition scale: A valid instrument for identifying and staging nursing home residents with dementia using the Minimum Data Set. *Journal of the American Geriatrics Society*, 42, 1173-1179.

Hartmaier, S.L., Sloane, P.D., Guess, H.A., Koch, G.G., Mitchell, C.M., and Phillips, C.D. (1995). Validation of the Minimum Data Set of cognitive performance scale: Agreement with the Mini-Mental State Examination. *Journal of Gerontology: Medical Sciences*, 50A, M128-M133.

Hawes, C., Morris, J.N., Phillips, C.D., Mor, V., Fries, B.E., and Nonemaker, S. (1995). Reliability Estimates for the Minimum Data Set for nursing home resident assessment and care screening (MDS). *The Gerontologist*, 35(2), 172-178.

Herzog, A.R., and Kulka, R.A. (1989). Telephone and mail surveys with older populations: A methodological overview. In M.P. Lawton, and A.R. Herzog, *Special research methods for gerontology* (pp. 63-90). Baywood Publishing Company, Inc.

Hughes, C.P., Berg, L., Danziger, W.L., Coben, L.A., and Martin R.L. (1982). A new clinical scale for the staging of dementia. *British J Psychiatry*, 140, 566-572.

Hughes, C.P., Berg, L., Danziger, W.L., Coben, L.A., and Martin, R.L. (1982). A new clinical scale for the staging of dementia. *British J Psychiatry*, 140, 566-572.

Kane, R.A. (1988). Assessing quality in nursing homes. *Clinics in Geriatric Medicine*, 4, 655-666.

Kane, R.A., and Kane, R.L. (1981). *Assessing the elderly: A practical guide to measurement.* Lexington, MA: D.C. Heath.

Kane, R., and Kane, R. (2000). *Measures, Indicators, and Quality of Life in Nursing Homes-Project Summary.* Presented at the Nursing Home CAHPS Methodological Expert Group Meeting.

Knauper, B. (1999). Age differences in question and response order effects. In N. Schwarz, D.C. Park, B. Knauper, and S. Sudman (Eds.). *Cognition, aging, and self-reports.* (pp. 341-363). Philadelphia, PA: Psychology Press

Koenig, H.F., and Kleinsorge, I.K. (1994). Perceptual measures of quality: A tool to improve nursing home systems. *Journal of Health Care Marketing*, 11(4), 2-13.

Korner-Bitensky, N., Wood-Dauphinee, S., Siemiatycki, J., Shapiro, S., and Becker, R. (1994). Health-related information postdischarge: Telephone versus face-to-face interviewing. *Arch Phys Med Rehabil*, 75 (12), 1287-1296.

Kovar, M.G., and Wright, R.A. (1973). An experiment with alternate respondent rules in the National Health Interview Survey. *Proceedings of the Social Statistics Section.* American Statistical Association, pp. 311-316.

Kruzich, J.M. (2000). Correlates of nursing home satisfaction. In J. Cohen-Mansfield, F.K. Ejaz, P. Werner, et al. (Eds). *Satisfaction surveys on long-term care* (pp. 76-100). New York: Springer Publishing Company.

Lavizzo-Mourey, R.J., Zinn, J., and Taylor, L. (1992). Ability of surrogates to represent satisfaction of nursing home residents with quality of care. *J Am Geriatr Soc,* 40(1), 39-47.

Levin, R., and Devereux, S. (1986). Surveying patient satisfaction by interviewing in person. *Dimens Health Serv,* 63 (5), 30-31.

Looman, W.J., Noelker, L.S., Schur, D., Whitlatch, C.J., and Ejaz, F.K. (1997). *Family members' perceptions of nurse assistants: More positive than nurse assistants think*. Cleveland Foundation Grant No. 93-0662. Benjamin Rose Institute.

Maas, M., Buckwalter, K., and Russell, D. (1986). *Evaluation of a special Alzheimer's unit: Phase I* (Grant no. 158) American Nurses Foundation. Washington, DC.

Magaziner, J. (1992). The use of proxy respondents in health studies of the aged. In Wallace RB, Woolson RF (Eds.). *The epidemiologic study of the elderly*. New York, NY: Oxford University Press, 120-9.

Magaziner, J. (1997). Use of proxies to measure health and functional outcomes in effectiveness research in persons with Alzheimer disease and related disorders. *Alzheimer Dis Assoc Disord,* 11(Suppl 6), 168-174.

Magaziner, J., Bassett, S.S. Hebel, J.R., and Gruber-Baldini, A. (1996). Use of proxies to measure health and functional status in epidemiologic studies of community-dwelling women aged 65 years and older. *Am J Epidemiol,* 143 (3), 283-292.

Magaziner, J., Hebel, J.R., and Warren, J.W. (1987). The use of proxy responses for aged patients in long-term care settings. *Compr Gerontol,* [B]1(3), 118-121.

Magaziner, J., Simonsick, E.M., Kashner, T.M., and Hebel, J.R. (1988). Patient-proxy response comparability on measures of patient health and functional status. *J Clin Epidemiol,* 41 (11), 1065-1074.

Mattiasson, A., and Andersson, L. (1997). Quality of nursing home care assessed by competent nursing home patients. *Journal of Advanced Nursing,* 26, 1117-1124.

McDaniel, C., and Nash, J.G. (1990). Compendium of instruments measuring patient satisfaction with nursing care. *Quality Review Bulletin,* 182-188.

Meister, C., and Boyle, C. (1996). Perceptions of quality in long-term care: A satisfaction survey. *Journal of Nursing Quality,* 10(4), 40-47.

Morishita, L., Boult, C., Ebbitt, B., Rambel, M., Fallstrom, K., and Gooden, T. (1995). Concurrent validity of administering the Geriatric Depression Scale and the Physical Functioning Dimension of the SIP by telephone. AHCPR Grant No. AG 11047. *Journal of the American Geriatric Society,* 43(6), 680-686.

Morris, J.N., Fries, B.E., Mehr, D., Hawes, C., Phillips, C., Mor, V., and Lipsitz, L.A. (1994). MDS Cognitive Performance Scale. *Gerontol Med Sci.,* 49, M174-182.

Morris, J.N., Hawes, C., Fries, B.E., Phillips, C.D., Mor, V., Katz, S., Murphy, K., Drugovich, L., and Friedlob, A.S. (1990). Designing the national Resident Assessment Instrument for nursing homes. *The Gerontologist*, 30, 293-307.

Mosely, R.R. and Wolinsky, F.D. (1986). The use of proxies in health surveys: Substantive and policy implications. *Med Care*, 24(6), 496-510.

Motsyn, M.M., Race K.E.H., Seibert J.H., Johnson M. (2000). Quality assessment in nursing home facilities: Measuring customer satisfaction. American Journal of Medical Quality, 15(2), 54-65

Mount, J.K. (1992). Nursing home responsiveness to research requests: Results of a field study. *Gerontologist*, 32, 414-419.

Murden, R.A., McRae, T.D., Kaner, S., et al. (1991). Mini-Mental State Exam scores vary with education in blacks and whites. *J Am Geriatr. Soc.*, 39, 49-55.

Noelker, L., Ejaz, F.K., Schur, D. (2000). Prevalence and problems in the use of satisfaction surveys: Results from research on Ohio nursing homes. In J. Cohen-Mansfield, F.K. Ejaz, P. Werner, et al. (Eds). *Satisfaction surveys on long-term care* (pp. 122-136). New York: Springer Publishing Company.

Ouslander, J.G., Tymchuk, A.J. and Rahbar, B. (1989). Health care decisions among elderly long-term care residents and their potential proxies. *Arch Intern Med*, 149(6), 1367-1372.

Parasuraman, A., Zeithaml, V.A., and Berry L.L. (1988). SERVQUAL: A multi-item scale for measuring consumer perceptions of service quality. *Journal of retailing*, 64, 12-40.

Pearson, A., Hocking, S., Mott, S. and Riggs, A. (1993). Quality of care in nursing homes: From the resident's perspective. *Journal of Advanced Nursing*, 18, 20-24.

Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *Journal of the American Geriatrics Society*, 23, 433-441.

Potter (2000), Patterns of Facility-Level Non-response in a National Survey of Nursing Homes. In preparation for the *Journal of economics and Social Measurement*

Potter, D.E.B. (1989). Nonresponse in a survey of nursing home residents. *Proceedings of the 1989 Section on Survey Research Methods, American Statistical Association.*

Potter, D.E.B. (1997). MEPS Nursing Home Component: Survey Nonresponse. *Presented at the International Conference for Health Policy Research, sponsored by the American Statistical Association, Health Policy Statistics Section and the American Public Health Association. Arlington, VA, December, 1997.*

Potter, D.E.B. 1988. Nonresponse in a survey of nursing homes and facilities for the mentally retarded: Findings from the National Medical Expenditure Survey, Institutional Population Component, facility data. *Proceedings of the Section on Survey Research Methods, American Statistical Association,* pp. 767- 772.

Potter, D.E.B. 1997. Are Response Rates for Nursing Home Surveys Declining? *Presented at the 1997 American Public Health Association Meeting, Indianapolis, IN, November, 1997.*

Rakowski, W., Mor, V., and Hiris, J. (1994). An investigation of nonresponse to self-assessment of health by older persons. *Journal of Aging and Health*, 6(4), 469-488.

Rantz, J.J., Mehr, D.R., Conn, V.S., Hicks, L.L., Porter, R., Madsen, R.W., Petrowski, G.F., and Maas, M. (1996). Assessing the quality of nursing home care: The foundation for improving resident outcomes. *Journal of Nursing Care Quality*, 10(4), 1-9.

Rantz, M.J., Mehr, D.R., Popejoy, L., Zqygart-Stauffacher, M., Hicks, L.L., Grando, V., Conn, V.S., Porter, R., Scott, J., and Maas M. (1998). Nursing home care quality: A multidimensional theoretical model. *J Nurs Care Qual,* 12(3), 30-46.

Rapp, C.G, Topps-Uriri, J., Beck, C. (1994). Obtaining and maintaining a research sample with cognitively impaired nursing home residents. *Geriatric Nursing,* 15(4), 193-196.

Reed, B.R., Jagust, W.J., and Seas, J.P. (1989). Mental status as a predictor of daily function in progressive dementia. *Gerentologist,* 29, 804-807.

Reich, W.T. (1978). Ethical issues related to research involving elderly subjects. *Gerontologist,* 18(4), 326-337.

Reidenbach, R.E., and Sandifer-Smallwood, B. (1990). Exploring perceptions of hospital operations by a modified SERVQUAL approach. *Journal of Health Care Marketing*, 10(4), 47-55.

Rogers, W.L., and Herzog, A.R. (1989). The consequences of accepting proxy respondents on total survey error for elderly populations. *Paper presented at the fifth conference on Health Survey Research Methods,* Keystone Colorado.

Rothman, M.L., Hedrick, S., and Inui, T. (1989). The Sickness Impact Profile as a measure of the health status of noncognitively impaired nursing home residents. *Med Care,* 27(3 Suppl), S157-167.

Rothman, M.L., Hedrick, S.C., Bulcroft K.A., Hickam, D.H., and Rubenstein L.Z. (1991). The validity of proxy-generated scores as measures of patient health status. *Med Care,* 29(2), 115-124.

Rubenstein, L.Z., Rhee, L., and Kane, R.L. (1982). The role of geriatric assessment units in caring for the elderly: An analytic review. *Journal of Gerontology,* 37(5), 513-521.

Rubenstein, L.Z., Schairer, C., Wieland, G.D., and Kane, R. (1984). Systematic biases in functional status assessment of elderly adults. Effects of different data sources. *J Gerontol,* 39, 686-691.

Rubinstein, R.L. (2000). Resident satisfaction, quality of life, and "lived experience" as domains to be assessed in long-term care. In J. Cohen-Mansfield, F.K. Ejaz, P. Werner, et al. (Eds). *Satisfaction surveys on long-term care* (pp. 13-28). New York: Springer Publishing Company.

Sainfort, F., Becker, M., and Diamond, R. (1996). Judgments of quality of life of individuals with severe mental disorders: Patient self-report versus provider perspectives. *American Journal of Psychiatry,* 153, 497-502.

Santos-Eggimann, B., Zobel, F., and Berod, A.C. (1999). Functional status of elderly home care users: do subjects, informal and professional caregivers agree? *J Clin Epidemiol,* 52(3), 181-186.

Schechter, S., Beatty, P., and Willis, G.B. (1999). Asking survey respondents about health status: Judgment and response issues. In N. Schwarz, D.C. Park, B. Knauper, and S. Sudman (Eds.). *Cognition, aging, and self-reports.* (pp. 265-302). Philadelphia, PA: Psychology Press.

Schnelle, J.F. (1997). Can nursing homes use the MDS to improve quality? *JAGS* 45(8), 1027-1028.

Schwartz, N., and Bless, H. (1992). Constructing reality and its alternatives: Assimilation and contrast effects in social judgment. In L.L. Martin and A Tesser (Eds.), *The construction of social judgements,* pp. 217-245. Hillsdale, NJ Erlbaum.

Schwarz, N. (1999). Self-reports of behaviors and opinions: Cognitive and communicative processes. In N. Schwarz, D.C. Park, B. Knauper, and S. Sudman (Eds.). *Cognition, aging, and self-reports.* (pp. 17-40). Philadelphia, PA: Psychology Press.

Simmons, S.F., Schnelle, J.F., Uman, G.C., Kulvicki, A.D., Lee, K.H., and Ouslander, J.G. (1997). Selecting nursing home residents for satisfaction surveys. *The Gerontologist,* 37(4), 543-550.

Simon, H. (1957). *Models of man.* New York: Wiley.

Slevin, M.L., Plant, H., Lynch, D., Drinkwater, J., and Gregory, W.M. (1988). Who should measure quality of life, the doctor or the patient? *Br J Cancer,* 57(1), 109-112.

Soberman, L.R., Murray, M., Norton, P.G., and van Maris, B. (2000). The domains of satisfaction in long-term care. In J. Cohen-Mansfield, F.K. Ejaz, P. Werner, et al. (Eds). *Satisfaction surveys on long-term care* (pp. 29-51). New York: Springer Publishing Company.

Sommers, J. (1993). Results of frame development and cleaning for the National Medical Expenditure Survey: Institutional Population Component Feasibility Study, *Proceedings of the International Conference on Establishment Surveys.*

Spalding, J.A. (1985). *A consumer perspective on quality of care, the residents' point of view.* Washington, DC, National Citizen's Coalition for Nursing Home Reform.

Sprangers, M.A.G., and Aaronson, N.K. (1992). The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: A review. *J Clin Epidemiol,* 45, 743-760.

Tennstedt, S.L., Skinner, K.M., Sullivan, L.M., and McKinlay, J.B. (1992). Response comparability of family and staff proxies for nursing home residents. *American Journal of Public Health,* 82 (5), 747-749.

Uhlman, R.F., and Pearlman, R.A. (1991). Perceived quality of life and preferences for life-sustaining treatment in older adults. *Arch Intern Med,* 151 (2), 495-497.

Uman, G., Hocevar, D., Urman, H.N., Young, R., Hirsch, M. and Kohler, S. (2000). Satisfaction surveys with the cognitively impaired. In J. Cohen-Mansfield, F.K. Ejaz, P. Werner, et al. (Eds). *Satisfaction surveys on long-term care* (pp. 166-186). New York: Springer Publishing Company.

Uman, G.C. (1997). Where's Gertrude? *JAGS*, 45(8), 1025-1026.

Uman, G.C., and Urman, H.N. (1997). Measuring consumer satisfaction in nursing residents. *Nutrition*, 13(7/8), 705-707.

Uman, G.C., Urman, H.N., and Hirsch, M. (1999). Satisfaction reports from nursing home residents with cognitive impairment: Presentation slides. *Vital Research*, LLC.

Van Maris, B. Norton, P.G., Soberman, L., Norton, P.G., and Murray, M. (1996a). Satisfaction of residents and families in long-term care: I. Construction and application of an instrument. *Quality Management in Health Care*, 4(3), 38-46.

Van Maris, B., Soberman, L., Murray, M., and Norton, P.G. (1996b). Satisfaction of residents and families in long-term care: II. Lessons learned. *Quality Management in Health Care*, 4(3), 47-53.

Van Wijck, E., Bosch, J., and Hunink M.G.M. (1998). *Time-tradeoff values and standard-gamble utilities assessed during telephone interviews versus face-to-face interviews*. 18(4).

Victor, C. (1988). *Some methodological aspects of using postal questionnaires with the elderly*, Elsevier Science Publishers (Biomedical Division).

Warren, J. W., Sobal, J., Tenney, J.H., Hoopes, J.M., Damron, D., Levenson, S., DeForge, B.R. and Muncies, H.L., Jr. (1986). Informed consent by proxy. An issue in research with elderly patients. *N Engl J Med*, 315(18), 1124-1128.

Weinberger, M., Nagle, B., Hanlon, J., Samsa, G., Schmader, K., Landsman, P., Uttech, K., Cowper, P., Cohen, H., and Feussner, J. (1994). *Assessing health-related quality of life in elderly outpatients: Telephone versus face-to-face administration*, The American Geriatrics Society.

West, M., Bondy, E., and Hutchinson, S. (1991). Interviewing institutional elders: Threats to validity. *Image - The Journal of Nursing Scholarship*, 23(3), 171-176.

Williams, S.G. (1992). Research considerations: Family opinions about elderly relatives in research. *Journal of Gerontological Nursing*.

Wingfield, A. (1999). Comprehending spoken questions: Effects of cognitive and sensory change in adult aging. In N. Schwarz, D.C. Park, B. Knauper, and S. Sudman (Eds.). *Cognition, aging, and self-reports*. (pp. 201-228). Philadelphia, PA: Psychology Press.

Zimmerman, S.I., and Magaziner, J. (1994). Methodologic issues in measuring the functional status of cognitively impaired nursing home residents: The use of proxies and performance based measures. *Alzheimer Dis Assoc Disord*, 8, s281-290.

Zinn, J.S., Lavizzo-Mourey, R. and Taylor, L. (1993). Measuring satisfaction with care in the nursing home setting: The Nursing Home Resident. Satisfaction Scale. *The Journal of Applied Gerontology*, 12, 452-465.

Websites

www.ltcq.com

Interviews by Experts

Albert, S. Columbia University, Gertrude H. Sergievsky Center. (March 14, 2000). *Use of proxies, cognitive screen.* Interview by Joan Buchanan.

Buckwalter, K. The University of Iowa, College of Nursing. (March 2000). *Cognitive screen, questionnaire content, mode of administration, use of proxies, sampling and casemix adjustment.* Interview by Shula Bernard.

Case, T. Consultant. (March 17, 2000). *Cognitive screen, questionnaire content, mode of administration, use of proxies, response rates, sampling and casemix adjustment.* Interview by Teta Barry.

Ejaz, F.K. The Benjamin Rose Institute (May 1, 2000) *Ohio Health Care Association Nursing Home Resident Survey and HealthRays Nursing Home Resident Survey.* Interview by Judy Sangl and Vasudha Narayanan.

Hawes, C. Myers Research Institute. (March 3, 2000). *Mode of administration.* Interview by Amy Stern and Joan Buchanan.

Gruber-Baldini, A. University of Maryland. (March 2, 2000). *Cognitive screen, questionnaire content.* Interview by Donna Rabiner.

Itkin Zimmerman, S. University of North Carolina-Chapel Hill, Cecil G. Sheps Center for Health Services Research. (April 18, 2000). *Sampling and casemix adjustment.* Interview by Julie Brown.

Johnson, T. Atlanta VA Medical Center. (March 2000). *Questionnaire content.* Interview by Shula Bernard.

Lawton, P. Philadelphia Geriatric Center (March 2000). *Cognitive screen, questionnaire content, mode of administration, use of proxies, response rates, sampling and casemix adjustment.* Interview by Diane Brannon and Teta Barry.

Mor, V. Brown University, Center for Gerontology and Health Care Research. (April 12, 2000, and April 14, 2000). *Sampling and casemix adjustment, cognitive screen, response rates.* Interview by Julie Brown.

Morris, J. Hebrew Rehabilitation Center for the Aged, Division of Social Gerontology. (March 3, 2000). *Cognitive screen, questionnaire content.* Interview by Shula Bernard and Nancy Hampton.

Norton, P. University of Calgary, Department of Family Medicine. (March 6, 2000). *Cognitive screen, questionnaire content.* Interview by Shula Bernard and Donna Rabiner.

Simmons, S. Jewish Home for Aging & Borun, Center for Gerontological Research. (March 3, 2000). *Cognitive screen, mode of administration, use of proxies*. Interview by Joan Buchanan.

Sloane, P. UNC-Chapel Hill, Department of Family Medicine. (March 1, 2000). *Cognitive screen, questionnaire content.* Interview by Donna Rabiner, and Nancy Hampton.

Teno, J. Brown University, Center for Gerontology and Health Care Research. (March 16, 2000). *Cognitive screening, questionnaire content, mode of administrations, use of proxies, response rates, sampling and casemix adjustment.* Interview by Amy Stern.

Uman, G. Vital Research Survey, LLC. (April 21, 2000). *Cognitive screen, questionnaire content, mode of administration, use of proxies, response rate, sampling and casemix adjustment.* Interview by Joan Buchanan.

Zinn, J. Temple University. (March 2000). *Cognitive screen, questionnaire content, mode of administration, use of proxies, response rates, sampling and casemix adjustment.* Interview by Diane Brannon and Teta Barry.